University of Alberta

Health Care Decision-making in Kugaaruk, Nunavut

by

Nancy A Edgecombe

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Abstract

The purpose of this study was to identify and describe the health care decision-making of the Inuit of Kugaaruk, Nunavut, a small, geographically isolated Inuit hamlet along Canada's Arctic coast. The population is predominantly Inuit. Missionaries in the 1930s and a health care system relying on nurses in an expanded role in the 1970s introduced biomedical medicine. An ethnographic research design was used which included participant observation, formal and informal interviews and available data. Fieldwork was conducted from mid-December 2002 to the end of December 2003.

The findings suggested two health decision-making processes: an illness orientated process and a health promotion/prevention process. The illness-oriented decision-making process was similar to that identified by Brink (1977) and Twaddle (1979) with two exceptions: the Inuit have no choice as to where to seek treatment and time is a major factor in their decision-making. The Inuit have become reliant on the biomedical health care system, which has replaced traditional healing practices. As a result the biomedical system is now the only choice when the choice available. The health promotion/prevention decision-making process was consistent with several of the health promotion and behaviour models. Health and wellness are closely associated with traditional values and activities, such as country foods and a strong connection to the land. Many of the health issues and concerns are linked, at least to some degree to a loss of traditional life skills and values.

Implications and recommendations for changes in health services, policy, and programs are explored. These include reevaluating nursing workload and staff mix,

evaluating existing health services and investigating new approaches to service delivery.

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CHAPTER 1
INTRODUCTION
Inuit Health Care

Little is known about the informal health care system of the Inuit. Before the influence of modern medicine, the Inuit's health system consisted of physical remedies and shamanistic practices, which centred on beliefs about the supernatural and its influence on the human condition. With the arrival of missionaries and traders came the introduction of both infectious diseases and basic biomedical treatments, which seem to have replaced traditional remedies as well as the shamanistic system. In many cultures, with the introduction and formalization of Western medicine, the traditional medical system became an informal or alternative system. This does not seem to be the case with the Kugaaruk Inuit. A series of interviews with elders of Kugluktuk (Irons, 1991) illustrates this. Although everyone had a story they had heard about shamans in the past, all denied personal experience with a shaman. Apparently, old remedies have been replaced by Western medications and treatments.

Health and the Inuit

Health is recognized as being a complex and multidimensional concept (Pender, Murdaugh & Parsons, 2002). The World Health Organization (WHO) defines it as "a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity" (WHO, 1978, p. 2). To reach this state, an "… individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities" (WHO, Health and Welfare Canada & Canadian Public Health Association, 1986, p.1).

Adolescent Inuit youth between the ages of 11 and 14 in Igloolik, Nunavut, described health in terms of physical, social, mental and, to a lesser extent, spiritual well-being (Shea, 1988). The health of the individual was closely linked to the health of the family; both individual and family health were strongly associated with an emphasis on traditional activities such as hunting, spending time on the land and

eating food from the land. Other factors that were found to contribute to good health were working hard, proper social behaviour, exercise and the avoidance of harmful substances. These youth "rarely defined health in terms of the absence of illness. Few denied that health and illness could coexist, and some elaborated that illness was a transient state superimposed on one's health" (Shea, 1988, p. 91).

Stairs (1992) found that Inuit identity and sense of self was closely linked to their worldview. This worldview encompasses both the physical and social environment. Being an *Inummarik* (genuine person) is not a state of being, but a life-long process of becoming a genuine person through interactions with people, animals and the environment. A positive sense of self is linked to one's relationship to other community members, social cohesiveness and a relationship to the land and to the animals that are the source of food, further supporting the link between health and social behaviour.

Health statistics for the Inuit were not distinguished from other Canadian aboriginal peoples until the mid-1990s. As a result, information on Inuit health statistics has been available only since that time. My personal observations, from working with the Inuit population for over 20 years, are that there are more people over the age of 60 today than there were 20 years ago, although life expectancy is lower than the general Canadian population by approximately 10 years (Statistics Canada, 1996a).

There is evidence that the incidence and acuity of certain disorders among the Inuit population differ from the general Canadian population. Inuit children have been found to have more frequent and severe lower respiratory infections that require hospitalization than the general population (Banerji et al., 2001), and rates of tuberculosis and sexually transmitted diseases (STD) remain high, despite health promotion and screening programs (Ferry, 1999). While less than five cases of HIV (Nunavut Department of Health and Social Services, 2004) have been reported in Nunavut, the rates of Chlamydia infections are significantly higher than other regions of Canada (incidence rate of 5200.7/100,000, compared to 300 for Canada (Nunavut Department of Health and Social Services, 2002)). Similarly, the incidence of sudden

infant death syndrome (SIDS) is eight times the national rate (Ferry, 1999), although, according to informants, none have occurred in Kugaaruk. The suicide rate of the Inuit in Nunavut is six times the national rate and suicide has affected most families and communities in the territory (Ajunnginiq Centre, 2004). Lung and colorectal cancers are 10 times higher than the national rate (Nunavut Department Health and Social Services, 2004). The incidence of diabetes and myocardial infarctions are significantly lower than the rest of Canada (Nunavut Department Health and Social Services, 2003b, 2004). For example, the mortality rate for myocardial infarction is 3.7/100,000, compared to 52.1 for Canada (Nunavut Department of Health and Social Services, 2004). Similarly, the mortality rate for stroke is 40.5/100,000, compared to 69.0 for Canada (Nunavut Department of Health and Social Services, 2004). However, with lifestyle and diet changes, this is likely to change.

The prevalence of some known high-risk behaviours is also higher in the Inuit population. Inuit woman smoke more than both southern Caucasian and Cree women. Inuit women are more likely to be inactive, and while they do not drink as often as southern women do, they drink more heavily when they do drink (Lavallee & Bourgault, 2000). The Inuit are more likely to live in overcrowded housing and be exposed to secondhand smoke (Banerji et al., 2001). Overcrowding is also associated with the spread of tuberculosis and other infectious and communicable diseases in the community (Health Canada, 1999a). Inuit between 12 and 19 years of age are five times more likely to smoke than the same age group elsewhere in Canada (Nunavut Department of Health, 2004). Inuit are more likely to be physically inactive with 67% reporting minimal physical activity (Nunavut Department of Health and Social Services, 2004). A number of studies identify physiological, social and environmental factors that are associated with the incidence of specific diseases, such as diabetes, hypertension (Young, 2003), otitis media (Bowd, 2005), and cardiovascular disease (Dewailly et al., 2001).

Purpose of Study

The purpose of this study was to identify and describe the health care decision-making of the Inuit of Kugaaruk, Nunavut.

Definition of Terms

Health Decision-making

"Health care decision-making" is the term used to denote any decisions made that relate to activities affecting the health of the individual or a family member.

Illness Management Decision-making. Activities related to management of a perceived illness or injury.

Health Promotion/ Prevention Decision-making. Activities meant to maintain and/or promote health.

Health Behaviour

"Health behaviour" is the term used to denote an activity of an individual or group that directly or indirectly affects the health of the individual or the group. "Health behaviour may be motivated by a desire to protect health by avoiding illness or a desire to increase one's level of health in either the presence or absence of disease" (Pender et al., 2002, p. 34)

Illness Behaviour

"Illness behaviour" is the term used to denote an activity of an individual or group carried out in response to an illness or exhibited symptoms. "Illness behaviour involves the monitoring of the body, the recognition and interpretation of symptoms, and remedial action (e.g., utilization of lay or professional help) to rectify the perceived abnormality" (Christakis, Ware, & Klienman, 1994, pp. 275-302).

Impetus for Research

The impetus for this research was my personal experience of working as a nurse practitioner in the central Arctic over a period of 20 years. This experience led to a realization that in order to provide care and services to the Inuit, it was necessary for health professionals to become familiar with the culture but also to understand the "inner workings" of the culture with regard to health. Research conducted as part of my Master's degree (Edgecombe, 1994) identified some differences in the values of the Inuit population in one community in comparison to other populations and health professionals. These experiences and research findings led to a questioning of the nature of the Inuit health care decision-making process and how it was influenced by

factors such as the incidence and prevalence of disease, socioeconomic environment and cultural values.

Research Methods

Ethnography, rooted in social and medical anthropology, provided the methodological framework for this study. In this manner, an emic perspective of the Inuit of Kugaaruk about health practices was elicited, to determine beliefs and values about health and how these translate into actions about health care decision-making.

"Ethnography" as a term describes a research design, a method of data collection and the product of research. It is a method of inquiry grounded in anthropology and the study of culture. The development of ethnography marked a shift from studying cultures by observing them objectively, to learning about cultures from the "native point of view" (Malinowski, cited in Ellen, 1984, p. 49). The aim is to understand the meaning of behaviours and events to the members of the cultural group themselves (Agar, 1996; Brink & Edgecombe, 2003). To this end, ethnography provides a means of investigating the cultural aspects of behaviours.

As a research design, ethnography is a "theoretically informed approach to the production of data" (Ellen, 1984, p. 9). Ethnographers seek to understand actions and events from the perspective of the cultural group (Spradley, 1980; Wolcott, 1987). The method allows for the study of the social reality of a specific cultural group, permitting the researcher to describe "the social reality of a particular [cultural] group" (Kleinman, 1992, p. 128). The focus of ethnographic research is a population as a whole. The entire population comprises the study sample and, therefore, to be manageable, the population must be small enough that individual members know each other, interact on a daily basis and are accessible to the researcher.

Ethnographic research does not use a single method of data collection. Rather, multiple methods are used conjointly. Within anthropology, ethnography has become synonymous with fieldwork and participant-observation. The researcher interacts with participants in their daily lives, observing and recording their behaviours and the researcher's impressions of these behaviours. Observations and interactions are documented in detailed field notes that serve as the data to be analyzed. Concurrently,

"key informants" are interviewed and questioned about their behaviour in order to delineate the meaning and values underlying their behaviour and to clarify and/or interpret what has been observed. Other methods of data collection are used as deemed necessary. These can include surveys, secondary analysis of existing data, literature, and media information. In addition, the researcher keeps a journal of activities, reactions, and thoughts about events and participation, which comprises part of the analysis.

An ethnography is also a product of research, as a narrative description of findings. In a narrative discourse, the researcher writes about the findings, attempting to bring an understanding of the participants' cultural reality to the reader. This often takes the form of relating and examining events that were observed and the explanations participants ascribed to those events.

For the purposes of this study, the field site was the small community of Kugaaruk in Nunavut Territory of the Canadian Arctic. This community was selected for several reasons: a) the history of the community indicated that due to environmental isolation, inhabitants had had limited direct contact with the dominant Canadian society until the mid-1950s; b) the community was small enough to provide me with the opportunity to observe most members of the population; c) the community was predominantly Inuit; d) the Inuit population comprised a homogenous group of the Netsilingmiut. In addition, there was support from the regional office of the Department of Health and Social Services, as well as from the community, to do research in Kugaaruk. Fieldwork was carried out over a 12-month period, from mid-December 2002 until the end of December 2003, during which time I lived in the community.

Entry to Community

Entry into the community, where the fieldwork was conducted, was a multi-stage, multi-faceted process. Health research in Nunavut requires at a minimum a research license from the Nunavut Research Institute, and support from the community and the Nunavut Department of Health and Social Services. The prerequisites for the research license from the Nunavut Research Institute were ethics

approval from the researcher's university and a letter of support from the community and the Department of Health and Social Services. Both the University of Alberta's Health Research Ethics Board and the Nunavut Research Institute had a formal application process. The Nunavut Research Institute's process included providing an Inuktitut version of a research summary and consent form consistent with the region in which the study was to be conducted. This was complicated by the fact that the University of Alberta Health Research Ethics Board and the Department of Social Services wanted the license approved before giving ethical approval, and the Department of Health and Social Service's support was dependent on acquiring a license. These multiple aspects of approval eventually coincided mid-December, allowing access to the field a few days before Christmas 2002.

Entering the field just before Christmas had several advantages, one of which was my visibility as a researcher in the community early in the field visit. During the Christmas season there were community activities daily, consisting of games during the afternoons and evenings, church services and dances during the night. By arriving just prior to this social period, I was able to introduce myself to key community members, such as the Hamlet staff, Health Centre staff, and school staff, prior to the Christmas closure of businesses. It also provided an opportunity to obtain maximum visibility in the community and to meet a large number of community members in a social setting and provide information on the study. It was through these initial contacts that formal and informal community leaders and community contacts were identified.

Following the Christmas season, translations of written materials, such as the consent form, were reviewed with local translators and amended as necessary. Posters (Appendix A) with my picture and a brief description of the study were posted around the Hamlet at key locations, such as the local store, post office and Health Centre. Local meetings of various community groups were attended and the purpose and nature of the research was explained.

Once established in the community, a continued presence was maintained by attending community events and meetings, regularly visiting the Hamlet offices, store

and the waiting area at the Health Centre. In this way, people got to know me, which resulted in my being invited into their homes and the identification of key informants who were interviewed.

Sampling

In ethnography, sampling refers to the selection and observation of events and the people involved in those events. Observed events included activities at the Health Centre, such as sick clinics, speciality clinics, public health clinics, and in the community, such as health committee meetings, prenatal cooking classes and food mail meetings; and public gatherings, civic meetings and private events, such as Christmas games, church services, Hamlet meetings, sports events, school graduations, community dances, community feasts, and organizational meetings (such as the Hamlet and Co-op AGMs), which I attended. Events were sampled repeatedly in order to identify health-related behaviours in various settings (such as smoking, foods provided and eaten at various functions and places, social interactions, and observable symptoms of illness in both children and adults. I observed and documented in detail any health or health-related behaviour (such as the types of food purchased at the local store), including my interactions with community members. Because of the public nature of these events and the size of the community, over the course of the research project, I observed most of the individuals in the community to some degree. In addition, I identified and approached specific individuals as key informants.

The selection of key informants was deliberate, in that informants were "chosen in a self-conscious way to obtain data for comparison with [existing data]" (Agar, 1996, p. 172). Informants were recruited from individuals who attended clinics at the local Health Centre, who expressed interest in or concern about health issues, who were identified by others as having knowledge and/or expertise in the area of health, community leaders, and individuals who self-identified as being willing to participate as informants. The goal in ethnography is saturation of data, and additional informants were sought until no new information was obtained. Key informants were also those individuals identified as having specialized knowledge in, expertise on or

insights into health beliefs and practices. These individuals provided me with more in-depth information and provided one source of verification for interpretation of the data. Eight individuals were identified as key informants and formally interviewed over the period of the field study. Three of these informants were male; five were female. Three were between 25 and 30 years of age, two were in their 40s and three were over 60 years of age. The number of interviews with these key informants ranged from one to four, depending upon the need to clarify issues and the availability of the informant.

Informal interviews were conducted with individuals who engaged in social conversation with me at community events. These interactions were documented in field notes. These informants ranged in age from 20 to 75 and were both male and female.

Data Collection

A number of different types of data are collected when conducting ethnography. The basic and primary method of data collection, considered the signature of ethnographic research, is participant observation (Agar, 1996; Brink & Edgecombe, 2003). This is considered the keystone of ethnographic research. While participating in the daily activities of the community, I observed activities within the community and documented these observations in field notes. While the focus of these observations was health-related behaviours, the observations took place in all venues accessible to me. Field notes were written either during or immediately following any observation of or interaction with informants. These notes consisted of observations about the event or interaction, a description of the setting, non-verbal behaviours, conversations, and activities of the individuals present. These notes were reviewed on a regular basis, looking for trends, inconsistencies, and anomalies. In addition, I analytically reviewed these notes on a regular basis, in order to generate questions and identify insights, themes, and research issues.

I also kept a diary of daily events, interactions, and meetings that occurred. This diary provided a framework for identifying and framing the activities and events

taking place in the community and with me during the field experience. I kept this activity diary on an ongoing basis as events occurred and reviewed it regularly.

At least daily, I documented my own activities and impressions in a personal journal. These notes were used to document impressions, feelings and reactions to the field experience and to reflect on observations, and help me identify subjective reactions to observations and interviews. Copies of all correspondence were saved for analysis.

Interviews took various forms, both formal and formal. Informal interviews were conducted with informants during interactions at events where observations were being made. These took the form of informal conversation. This allowed me to immediately seek further clarification about the meaning of the activity and to ask questions about the meaning of health care decision-making activities within specific contexts and with respect to specific events. The content of these interviews was documented in my field notes.

Formal interviews took place with key informants, based on questions arising from informal interviews, field notes, and other sources of information. The focus of these interviews was to identify the health care decision-making process and the meanings behind the activities identified in the process. These interviews consisted of open-ended questions and were tape-recorded. Initial interviews were analyzed in relation to the meaning of health-related behaviour. Subsequent interviews were used to clarify and modify concepts related to health care decision-making, and look for relationships among these concepts that would help in the understanding of events related to health care decision-making.

Other sources of data included the analysis of external sources of health information. Media information, consisting of health bulletins, the two territorial newspapers and territorial news broadcasts on both radio and television, were included as data sources of information about current health issues in the community and health care decision-making. Historical records were used to elicit data about health issues and health care decision-making behaviours over time. These included ethno-historical records and personal accounts, such as biographies, stories, and an interview with an

anthropologist visiting the community who had done ethnography in the community 40 years earlier. When available, Health Utilization Data from the Department of Health and Social Services, Nunavut, was used to determine the health and illness morbidity data for the population of Kugaaruk, and the types of health behaviour for which people commonly sought help from the formalized health system. Information from patients' charts was not accessible, so specific information about individuals and their health was obtained from them or through observation (e.g. number of medivacs for bronchiolitis). In addition, minutes of meetings, videos, snapshots, and published diaries were used.

Data Analysis

Data analysis in ethnography is a complex and ongoing cyclical process. As there are multiple methods of data collection, each was analyzed separately and then compared during the analysis process. Field notes were reviewed regularly, in order to identify health-related behaviours and to derive questions to be asked about those behaviours in order to understand the meaning underlying the behaviour. In addition, journal notes were reviewed to identify my response to participation and how these responses might have influenced data collection. Transcripts from interviews were analyzed to identify and confirm repetitive health-related symbols and themes, and to identify future questions. Other data were analyzed for patterns and congruence; with the data I had already generated. The product of analysis was the identification and definition of the process of health care decision-making and the cultural concepts. All objects and experiences were conceptualized within a socio-cultural context.

Reliability

Reliability refers to the "stability of research results and their ability to be replicated by other researchers" (Schensul, Schensul, & LeCompte, 1999, p. 271). In ethnographic research, reliability is "concerned with the consistency, stability, and repeatability of informant's accounts and the investigator's ability to collect and record information accurately" (Brink, 1991, p. 176). Informant reliability was achieved by several means. By interviewing informants repeatedly over time and asking questions on the same topic over a period of time, information obtained across

interviews was consistent. In addition, the findings of taped interviews were shared with informants for clarification and confirmation. Investigator reliability is achieved through constantly testing observations and the understanding of observations with key informants. In this way, information is continuously verified and clarification sought.

Validity

Validity refers to "the degree to which scientific observations actually measure or record what they purport to measure" (Pelto, 1970, p. 41). In this ethnographic study, validity was achieved in several ways. I constantly checked observations and my understanding with informants for verification and further clarification. Observations and interviews took place over a period of time, which allowed me to verify behaviours and the understanding of these behaviours. In addition, in ethnography, validity was accomplished through the multiple methods of data collection and the triangulation of resulting data.

Ethical Considerations

Ethical approval for conducting this research was obtained from the University of Alberta Health Research Ethics Board. The process of gaining permission to do health research in Nunavut required several steps, as previously mentioned. Support for this study was obtained from the Kitikmeot Health and Social Services Office, which administers health services in the Kitikmeot Region of Nunavut, where the study was conducted. Concurrently the Kugaaruk Hamlet Council permission and support for the project was obtained. Finally, a license from the Nunavut Research Institute was obtained. As part of the agreement with the Hamlet of Kugaaruk and the Nunavut Research Institute, copies of the completed research study will be provided to them in addition to an executive summary, which will be translated into Inuktitut.

There was no direct benefit or risk to the participants. There was an essence of risk due to the length and nature of ethnography. There was the potential for informants, over the course of the research project, to disclose information unintentionally. To minimize this potential, I continued to identify myself as a

researcher at events and during interviews. Individuals had the right not to talk to me, and key informants had the ability to withdraw their participation at any time.

Informed consent was obtained in several ways, depending on the setting. Upon my arrival in the community, I met with community leaders and provided an explanation of the study, both verbally and in written form (see Appendix B), in both English and Inuktitut. I posted notices on public bulletin boards (see Appendix A). I provided key informants with information about the study (see Appendix B),including that participation in the study was voluntary, that they could withdraw from the study at any time, and that non-participation would not result in recrimination or harm to themselves or others (see Appendix B). A number of people did choose not to participate, which indicates that people felt comfortable with the process. Written consent was obtained for formal interviews (see Appendix C). Participants in informal interviews were informed of the study (see Appendix D), and if requested, were given a more detailed information sheet (see Appendix B).

Informants were not identified by name or initials in transcripts, field notes or in the reporting of data. A number was assigned to identify each informant throughout the study. The master list, matching informants with number, is kept in a secure, locked location, separate from other data. Only I have access to the master list. Similarly, I keep tapes, transcripts and field notes in a secure location

CHAPTER 2

HEALTH CARE DECISION-MAKING

People rarely think about their health activities and behaviours, yet each activity and behaviour involves a series of decisions made by the individual, either independently or as part of a social group. This health care decision-making is the basis for how people behave in order to prevent and/or manage illness. Understanding why and how people make decisions will allow health professionals and policy-makers to plan and implement programs that will be better utilized. By observing health behaviour and exploring the values and beliefs associated with that behaviour, and the decisions made related to that behaviour, such an understanding could be gained.

Decision-making

Decision-making is a common human activity. In fact, each of us makes hundreds, if not thousands, of decisions each day, and has done so since early childhood. Every action in our lives involves a decision of some sort. Decision-making is the act of choosing between alternatives (Schermerhorn, Hunt, & Osborn, 1997). Most of the decisions we make are so routine and familiar that we are no longer consciously aware of either the decision or the cognitive process of the decision-making itself.

Values are integral to decision-making (Frisch & Clemen, 1994). "They are basic to our preferences and our decisions and give meaning to all we do" (Werkmeister, 1967, p. 59). We share values with those close to us, which allows us to share standards of behaviour, and, as such, values are a cultural phenomenon.

Decisions can be made in several ways. An individual can independently evaluate and choose between alternatives. The simplest decisions about activities of daily living are made in this way. Second, an individual can share the decision-making with others and together they can evaluate and choose from alternatives. Third, the individual can be advised as to the best alternative by someone in a position of authority, who is considered more knowledgeable and who is credited with more expertise than the individual (Gwyn & Elwyn, 1999). Regardless of how decisions are

made, the process is part of a complex feedback mechanism, in that all decisions are either consciously or unconsciously based on numerous internal and external influencing factors, which are subject to change.

Health Care Decision-making

Health care decision-making refers specifically to those decisions made that relate to illness management, health promotion and disease prevention. Decision-making related to health care with respect to illness management is not a single event but rather a series of events, each requiring decisions to be made. These events occur over a period of time, starting with the identification of an altered state of health and continuing until the illness has been managed. These events include the identification, labelling, treating, and resolution of the illness episode. Health promotion and disease prevention decisions deal with those activities an individual undertakes in order to minimize his or her risk of illness or to identify disease at an early stage so as to maximize available treatment regimens. In the Western biomedical system, these activities include immunization and screening for diseases such as cancer, diabetes, and hypertension, and may involve procedures such as mammograms.

Health and illness take place within a cultural context, providing individuals, families, and community members with culturally specific beliefs and knowledge, which influence and direct their behaviour and activities. Health and normal healthy behaviour are social constructs that are defined within every culture (Berkman, 1981; Kleinman, 1978). One definition of health is being able to maximize one's potential physically, mentally, and spiritually (WHO, 1978; WHO et al., 1986). In the dominant North American tradition, that means being able to continue activities of daily living, including work. Illness interferes with one's ability to perform some or all aspects of the activities of daily living. Culture defines which deviations from behavioural norms are considered illness, and which are considered unacceptable for other reasons. Culture, therefore, underlies the decision about whether one is ill, and to whom a person goes for what, including what options are available and desirable.

While a person's health and illness behaviours can be observed, it is more difficult to determine the decision-making that resulted in these behaviours. Most of

the time, individuals themselves are not consciously aware of the process of their own decision-making. In order to elicit the decision-making process, identification of specific behaviour and inquiry into the thought process that led to that behaviour is required.

Process of Illness Management Decision-making

The process of managing an illness can be divided into a number of events or steps (Brink, 1977; Twaddle, 1979). Each of these events requires decision-making. Brink identified five events, while Twaddle identified seven events.

The first step identified by Brink (1977) was the decision that the person was ill. This decision was made based on the impairment of the person's normal functioning and the past experience of the individual and his/her family with the symptoms. The subjective statements made by the individual and the observations noted by other family members influenced the assessment of the degree of impairment of normal functioning. Experience of the symptoms included eyewitness or personal experiences, as well as hearsay.

The second step identified by Brink (1977) centered on whether the individual required assistance and the type of assistance required. If it was decided that assistance was required, then the type of assistance needed to be identified. Assistance fell into two categories: professional or non-professional. The decision was based on the crisis nature of the illness; the degree of impairment in functioning; the status of the individual in the family; and the family's resources. If it was decided that a healer was necessary, then decision-making was required in order to determine which healer was is most appropriate. The two key considerations at this point were the availability of the healer, and the past experience with the healer. The availability of the healer was judged based on the distance that needed to be travelled to reach the healer; the transportation necessary to access the healer; and whether services were available with a home visit, or whether a visit to the healer's place of practice was required. Past experience with the healer included both eyewitness and personal experience and the resulting trust in the capabilities of the healer to diagnose, heal, and charge reasonably,

and his or her willingness to accept the individual as a patient. Hearsay accounts of the healer's expertise and fairness would also be considered.

Once a healer had been engaged, a decision would be made by the individual and family about whether to remain with the healer for the entire treatment process. This decision was based on whether the healer agreed to treat the individual; the conditions associated with the treatment plan; the acceptability of the diagnosis and treatment plan by the individual and family; and, finally, the improvement in the patient's condition as a result of treatment. The family's agreement with the diagnosis and treatment was influenced further by the status of the patient within the family and the reasonableness of the healer's fees and other treatment costs.

The fifth and final decision-making event, again by the individual and his or her family, was the decision that the individual was well. This decision was based on whether all the treatment conditions had been met, an observable improvement in the patient's condition, and the patient's ability to return to normal functioning.

Twaddle (1979) also used a case study approach to identify a sequence of seven decisions in the illness experience. The first decision is actually external to the illness experience, but provides the baseline for determining the state of well-being. This first decision is that a person is healthy. This decision can be based on several factors: the absence of symptoms, the expectation of not being sick, or the resolution of a previous illness state. This decision provides the baseline for what is normal healthy functioning for this person.

Similar to Brink (1977), Twaddle (1979) maintains that the second decision comprises the recognition of some change from normal functioning, and that this change is outside of what can be attributed to "artefacts of normal living" (Brink, 1977, p. 322). This leads to the exploration of changes with family and friends, which results in the consideration of various treatment possibilities. Both Brink and Twaddle suggest that the change in normal function to the degree that it is identified by others is an integral step in the decision-making process. Brink includes in this step the assessment of the severity of the illness, while Twaddle identifies assessment as an independent third step in the decision-making process.

Twaddle's (1979) third decision involves the assessment of the severity of the deviation from normal functioning, based on the degree of interference with normal activities or the characteristics of the patient. The greater the interference with normal activities or the more changes noted in the individual, the more serious the illness will be considered.

The fourth decision identified by Twaddle (1979) is whether the person and family can treat the illness, or whether they need assistance from health professionals. Commonly, self-treatment will be attempted prior to seeking assistance from other sources. In fact, in many cases, several self-help alternatives are tested before medical treatment is requested. In contrast, Brink (1977) includes this evaluation as part of the assessment of the severity of the illness, in which the family's resources and ability to manage the illness are among the factors evaluated.

Once the decision has been made about whether to self-treat or to seek treatment from health professionals, the fifth decision is to determine the type of treatment agent (Twaddle, 1979). Which remedy within the self-treatment alternatives will be used? What type of healer should be accessed? Depending on the traditions of the individual and his or her family, several alternative healers may be deemed appropriate.

After the type of treatment agent has been established, the sixth decision is made: which particular agent is to be accessed? The decision to choose between healers of the same sort is primarily based on accessibility, experience, and comfort level (Twaddle, 1979).

The seventh decision relates to the degree and type of cooperation that will be afforded the treatment plan (Twaddle, 1979): which parts of the treatment plan will be followed and which will be ignored. "Cooperation is greater when the treatment falls within the expectations of the patient and her or his group" (p. 323). Cooperation is also greatly influenced by the support of family and friends and the degree to which the patient is involved in treatment planning. This is similarly outlined in Brink's (1977) fifth step in the decision-making process.

Despite the seeming discrepancy between the decision-making processes as described by Brink (1977) and Twaddle (1979), there are common event points:

1. An illness state must be identified and categorized;
2. Possible healers or treatment choices must be identified, evaluated and selected;
3. Treatment must be evaluated and selected; and
4. The end of the illness must be identified.

One major difference between the two processes is the identification of the end of illness. Brink identifies this decision as the final step in the process, thereby lying within the scope of the individual and family. Twaddle, in contrast, does not recognize the identification of the end of the illness as part of the decision-making process, but rather an "end point" (p. 324) external to the individual and family decision-making process. The end of illness was marked by the return to normal health, by death, or by stability at a chronic level. This difference is important to note, as there are significant implications. In the process suggested by Brink, the decision that the person is well is made by the person or the person's family, while in the process described by Twaddle, the decision is external to the decision-making process and made by others, such as physicians.

The possibility exists that these identified decision-making events are themselves influenced by the culture being studied. Brink's (1977) study was conducted in an economically poor, rural Nigerian setting dominated by kinship ties. Three major health care options were available: traditional healers within the village; local "nurses" or villagers with some experience in Western biomedicine; and the Western biomedical system which was available at a distance from the village, and only accessible by walking, bicycling or by hiring transportation. All decision-making occurred within a kinship context by the oldest male members of the family. This was the cultural context of the health/illness cases. On the other hand, Twaddle (1979) conducted his study in the United States, dominated by the Western health care delivery system, which essentially placed all control over medical decision-making in the hands of health professionals, primarily physicians. Not surprisingly, Brink

identified the decision that the patient was well as being made by the family and as part of the health decision-making process, while Twaddle did not identify that this decision rested with the family at all, but was made by professionals and external to the illness management decision-making process.

The cultural context of illness management decision-making is critical to an understanding of the patient or family's decision-making process. The choice between decision-making alternatives demands that the alternatives be identified within the context of the situation. If there is no alternative, there is only one decision—either for or against that one alternative. If more than one alternative exists, then choices must be made between them and ranked according to their "best fit" with the situation. Available alternatives are frequently sociocultural in nature. What is most surprising about the decision-making processes described and identified by Brink (1977) and Twaddle (1979) is the similarity between the two sets of processes, in spite of the significant differences in their cultural contexts.

The multi-step decision-making processes identified by Brink (1977) and Twaddle (1979) demonstrate the intricacy of the illness management decision-making process, in which each step is in itself a complex decision process and is affected by physiological and sociocultural factors. Physiological factors relate to the genetic and biological characteristics of the individual and the pathophysiology associated with illness. Sociocultural factors relate to the social and cultural attributes of the individual, his or her social group and society in general. While sociocultural factors are separate from physiological factors, they are interpreted through values and beliefs, which themselves are sociocultural in nature.

Both Twaddle (1979) and Brink (1977) agree that individuals include family and friends in the illness management decision-making process. The degree of involvement will vary with the event and the comfort level of the individual in making the decision independently of his or her social group. Family and friends have been found to be a significant source of information about and influence on treatment alternatives (McNeilly & Hillary, 1997). Each decision-making event results in a

behaviour, and each behaviour must be explored to determine the nature of the decision-making process for that event.

The Process of Health Promotion/Prevention Decision-making

A number of theories and models have been suggested to explain health promotion and disease prevention activities. Fishbein and Ajzen (1975) proposed theories to explain decisions made about health behaviour, which they called the Theory of Reasoned Action and the Planned Behaviour Theory. The Theory of Reasoned Action holds that health behaviours are influenced by attitudes towards a specific behaviour, and subjective norms. Attitudes are the result of beliefs about the consequences of the behaviour and the evaluation of the effect of the consequences. Subjective norms are the expectations of significant others, such as family members, regarding behaviour. These expectations motivate us to behave in particular ways. In addition, health behaviour and decisions are affected by the perceived behavioural control, which is explained by the Planned Behaviour Theory. This theory proposes that the individual's perception of his or her behavioural control is influenced by beliefs concerning "opportunities to engage in the behaviour" and the "power of various factors to inhibit or facilitate the behaviour" (Pender et al., 2002, p. 39). Health behaviours and health care decisions are, therefore, the result of an individual's attitude and the subjective norms, which influence both the individual and the locus of control of the behaviour. This is consistent with the processes outlined by both Twaddle (1979) and Brink (1977), in that decisions are influenced by the health beliefs of the individuals and their friends and families-and with consideration of resources and availability of treatment regimens

The Health Belief Model (Becker, Drachman, & Kirscht, 1974; Becker et al., 1977) postulates that decisions about health are based on individual perceptions concerning their susceptibility to a disease and the perceived seriousness of the disease. These individual perceptions are modified by external factors, including ethnicity, social class, peer and reference group pressure, knowledge about disease, prior contact with the disease, mass media campaigns, and advice from others. The resulting perceived threat of the illness and the perceived benefit of action will

determine what action, if any, will be taken. While this does not explain the process of health care decision-making, it reinforces the premises put forward by Brink (1977) and Twaddle (1979) that decisions are at least in part influenced by one's social group, past experience and hearsay.

Similarly, Cox (1982), in the Interaction Model of Client Behaviour, identifies background variables that influence client behaviour. These background variables include demographic variables, social influence, previous health experience, and environmental resources. Health behaviour is considered to be the result of intrinsic motivation, cognitive appraisal and affective response, which are influenced by both background variables, and by the nature and expectations of client-professional interactions. These client-professional interactions are mitigated by affective support, health information, decision control, and professional/technical competences. Health behaviour outcomes can be evaluated with regard to utilization of health services, clinical health indicators, the severity of the health care problem, adherence to the recommended regimen, and satisfaction with care. This model recognizes the role of background variables in influencing expectations regarding health. Health behaviour is linked with social influences, previous experience, resources, and expectations of the client-professional interaction. This model supports the premise that health care decision-making has a sociocultural component and, as suggested by Brink (1977) and Twaddle (1979), is influenced by both one's social group and by the perceived competences of healers. It also supports Brink's premise that health care decision-making is influenced by resources and by satisfaction with care/treatment.

The Protection Motivation Model (Pender, 1996; Plotnikoff & Higginbotham, 1998) attempts to explain why individuals adopt, or fail to adopt, certain health behaviours in order to reduce risk or to protect themselves from future ill health. This theory postulates that an individual will be motivated to adopt a healthy behaviour if the appraised threat is strong enough, and the appraised ability to cope is high enough. The appraisal of threat is based upon the person's estimation of the threat (perceived severity) of a disease and the estimation of the likelihood of contracting a disease (perceived vulnerability). In turn, these are influenced by the perception of the reward,

both internal and external, of avoiding the disease. The appraisal of coping ability is based upon the individual's expectation that the behaviour will result in reducing the threat of the disease (response efficacy), the individual's belief that he or she will be able to execute the behaviour (self-efficacy), and the costs of responding. This theory identifies four key motivations for changing health behaviour: a) the severity of the threat, b) the vulnerability to the threat, c) the effectiveness of the response in reducing the threat, and d) the individual's ability to execute the change in behaviour. All of these motivations are mediated by the rewards and costs of changing the behaviour. While this theory may be useful in evaluating lifestyle behaviours that are considered risk factors for disease, it has not been established whether these behaviours influence the health care decision-making process in acute situations.

Sociocultural Context of Health Care Decision-making

Health care decision-making and the resulting behaviours take place within a sociocultural context. Certain social characteristics are shared within our social group of family, friends, and co-workers, which is part of a wider cultural unit. We share attitudes, beliefs, and values with those around us, and these are integral to how we make health care decisions and what we do about illness. A person's strongest sociocultural affiliation is usually with his or her nuclear or extended family, and health care decision-making is learned through interactions with other family members while growing up (Bomer, 2004). As people expand their experiences outside the family, they meet others, either as friends or peers, and this broadens their knowledge about the values and beliefs others use to make health care decisions. These experiences can either reinforce the decision-making process learned within the family or introduce new perspectives. Further, the broader societal norms to which we are exposed through school, mass media, and other experiences introduce us to other values, beliefs and alternatives, and influence our health care decision-making.

Each of us has a unique collection of life experiences, which also affect the health care decisions we make by influencing the sociocultural factors that frame our worldview. Sociocultural factors—which include values, beliefs, education,

experiences, socioeconomic position, religion and environment—influence the way we think and the decisions we make.

Beliefs are the ideas and concepts that the individual holds to be true and represent how things are in the world. Health beliefs include convictions about the cause of illness, the validity ascribed to each of various treatment modalities available, and expectation regarding treatment regimens.

An individual's values are developed from contact with others in the social world. They are "the standards we live by, the goals we hope to achieve. They are basic to our preferences and our decisions and give meaning to all we do" (Werkmeister, 1967, p. 59). Values differ from beliefs in that there is a feeling attached to values, which attaches a moral judgement of good and bad (Parsons, 1962). In health care decision-making, values influence how we judge alternatives at each decision point.

Emotions are the feelings and passions that influence our activities. Depending on the situation, emotions can have a great impact on health care decision-making. Illness is often associated with emotions such as fear and stress. The more serious the illness, the greater the fear and the more stress associated with the decision-making process. Individuals may evaluate alternatives with an emphasis on reducing emotion rather than on the illness episode. This can result in the over-utilization or under-utilization of alternatives. Mechanic and Volkart (1961) identified stress as a factor in health care utilization. Their research found that individuals were more likely to assume the sick role and to seek medical services when experiencing increased stress in their lives.

Both formal and informal education can influence the decision-making process by providing the decision-maker with better knowledge and understanding of the alternatives available and the consequences of these alternatives. Formal education is a structured, purposeful learning experience, which includes activities such as school and apprenticeships. Informal education occurs as a result of the process of socialization through modeling and enculturation. Through education, we learn about

the causes of illness, prevention, and the appropriate alternatives necessary for health care decision-making.

We share, through socialization, many life experiences with our families and cultural group. In addition, each of us has our own unique experiences, which may or may not be congruent with the experiences of our family or the cultural norms. These experiences may influence our worldview and our behaviour. Through these experiences, the sick role is defined and acceptable alternatives are identified and evaluated. The more alternatives to which one is exposed, the greater the possible choices of treatment. In addition, past experience with an alternative will influence how it is evaluated as a possible option at other times (Sharma, 1991).

Social class and economic resources also affect health care decisions. Health care alternatives while considered and valued, may be inaccessible because of socioeconomic factors. Individuals from the lower socioeconomic groups do not access many alternatives because of the costs involved (Graham et al., 2005; Stewart et al., 2005). Even when access to physician care is covered, the cost of the treatment regimen may be the responsibility of the individual and may influence "compliance". Other factors, such as transportation and health care provider behaviours can also influence decisions to use health care services (Stewart et al., 2005).

Religious/spiritual beliefs may also influence the decision-making process in many ways. Chiu, Ganesan, Clark, and Morrow (2005) found that spirituality affected the decisions made by South and East Asian immigrant women in British Columbia, Canada, with regard to serious mental illnesses. In this study, religion was seen to influence "ideas of what constitutes being mentally healthy or mentally ill" (Chiu et al., 2005, p 645), and where to seek treatment (as well as from whom). Religious/spiritual beliefs may also influence which alternative will be acceptable. Jehovah's Witnesses refuse blood transfusions on religious grounds. In many cultures, there is a supernatural aspect to many illnesses, and treatment may therefore require a spiritual component (Chiu et al., 2005). Within traditional Javanese culture, treatment regimens incorporate both herbal remedies and the casting of spells to call upon the patient's guardian spirits to chase the spirits causing the illness (Geertz, 1977). Waters

(2001) found that the spiritual beliefs of African Americans influenced their decisions about end-of-life decisions. There was a strong belief that God had a plan, so they did not need to make plans themselves. Many expressed the view that making a living will was comparable to assisted suicide. In the Judeo-Christian tradition, there is a history of illness being seen as a penance for sin or the will of God (Sigerist, 1977).

The environment can influence the decision-making process in several ways. Environmental factors may themselves be associated with health or illness. The accessibility of alternatives may be influenced by factors such as distance to services or availability of resources, including raw materials for treatment (Brink, 1977).

The individual lives and works within a social context and, to promote social harmony, will share values and beliefs with his or her social network. Decision-making alternatives are often evaluated, at least in part, by the norms and values of the social group (Chiu et al., 2005). The primary social group for most individuals is the family, followed by friends and co-workers. It is common for individuals to include family and friends in the decision-making process. The degree of involvement will vary with the event and the comfort level of the individual in making the decision independently of his or her social group. Family and friends have been found to be a significant source of information and influence about treatment alternatives (McNeilly & Hillary, 1997).

Over the past decade, the media has steadily gained more and more influence over the decisions people make in general. In recent years, health issues, treatment alternatives and their critics have found their way into the public media. Magazines advertise both pharmaceutical and alternative treatments for ailments. Television provides consumers with dramatizations, documentaries and infomercials about illnesses and possible treatments. The Internet allows individuals to seek out and explore information about illnesses and treatment alternatives. A study of the influence of media coverage and physician advice on the utilization of breast cancer screening (Yanovitzky & Blitz, 2000) found that media coverage did significantly influence women who had no regular access to a physician to participate in mammogram screening for breast cancer. In a study on the sources of nutritional

information of older adults, newspapers and magazines were relied on as often as doctors, which was followed by television, then other health professionals, then family and friends (McKay, Houser, Blumberg & Goldberg, 2006). Media campaigns have been found to be effective in reducing cardiac risk in a number of studies, especially in conjunction with other health promotion activities, such as community screening activities (Parker & Assef, 2005).

All cultural groups participate in forms of illness management; however the experience of illness occurs as a social phenomenon and is greatly influenced by culture. At each decision point, societal cultural norms come into play. In order to understand and respond to illness of individuals from different cultures, it is essential that cross-cultural understanding and adaptation in health care occur. A number of studies have illustrated that there is cultural variation, both in which services are used and in how they are utilized.

Suchman (1965) recognized that physicians and patients not only perceived and interpreted symptoms and illness differently, but also differed in the "relative reliance they placed upon the scientific or formal approach to medical care as compared with the more personal, popular or folk means of treating illness" (p. 2). Suchman's research examined the relationship between social group orientation and individual medical orientation of immigrant populations in New York City. Individual medical orientation consists of the individual's knowledge about disease, scepticism of medical care and dependency in illness. He identified a relationship between these three aspects. Those individuals who demonstrated lower levels of knowledge about disease were found to be more sceptical of medical care and have higher dependency during illness. Social group orientation entailed the relationship between ethnic exclusivity, friendship solidarity and family tradition and authority. Suchman concluded that the stronger the identification with ethnicity of the individual, the more likely friendships would be of a long-term nature and the more reliance there was on family (cultural) customs and traditions.

Suchman (1965) found strong association between social group orientation and individual medical orientation. The stronger the social group orientation, the more

likely the individual would be to have a lower level of knowledge about disease, and a higher level of scepticism toward medical care and dependency in illness.

Geertsen, Kane, Klauder, Rindflesh, and Gray (1975) studied the relationship between social group orientation and individual medical orientation in a more culturally homogenous group in Salt Lake City. They found variation in the nature of the relationships within and between the social group and individual medical orientations. In this population, there was no significant relationship between knowledge about disease, and scepticism about medical care or dependency in illness. There remained, however, a relationship between scepticism of medical care and dependency in illness. Perhaps the most interesting finding was the relationship between the orientations, which was dissimilar to Suchman's findings (1965). In this population, high family authority and strong friendship solidarity were associated with low scepticism. Consistent with the Suchman study, there was a strong relationship between dependency and both family authority and friendship solidarity. These findings suggest that the relationships may differ between cultures.

Cultural Research and Health Care Decision-making

In recent years, health care decision-making research has focused on identifying factors that influence people to participate in treatment regimens (Dracup, Moser, Eisenberg, Meischke, Alonzo, & Braslow, 1995; Hunter, O'Dea, & Britten, 1997; Kittell, & Mansfield, 2000; Pellissier & Venta, 1996: Yamamoto & Wallhagen, 1998) or on how to influence the decisions individuals make about treatment regimens (Hilton & Starzomski, 1994; McCaffery et al., 2001; Milewa, Calnan, Almond, & Hunter, 2000; Reece, 2002). The assumption seems to be that non-participation or non-compliance is negative, and that by understanding such behaviour, measures can be taken to change this behaviour. The focus of much of this research implies that non-compliance is a problem and by identifying the cause of the non-compliance, it can be corrected.

Underlying all the research on health and illness behaviour is the acknowledgement that health care decision-making is based on multiple interactive variables. These variables all have a cultural component, which strongly influences

how individuals identify and classify illnesses and the actions they take to both prevent and manage illness.

Much of the cultural research related to health care decision-making examines how different cultures classify disease and utilize both traditional and Western treatment modalities. These studies illustrate how cultural groups have incorporated Western medicine into their explanatory models, while maintaining varying degrees of their traditional health and illness belief systems.

The response of the Bondei of the United Republic of Tanzania to malaria illustrates the relationship between cultural considerations and health care decision-making (Oberländer & Elverden, 2000). The Bondei identify malaria as an illness and have adopted both the biomedical explanation and treatment regimen for the disease. They also have three traditional diseases that are symptomatically similar to malaria: *degedge, mchango* and *kibwengo. Degedge* is a result of bad luck and causes convulsions, high fever, diarrhoea and shivers in small children. It must be treated locally, using traditional intervention. *Mchango* is caused by worms in adults and bad luck in children and is characterized by fever, cold hands and feet, general body weakness, and, eventually, convulsions. It can be treated either by local healers or by using Western medicine. *Kibwengo* is caused by the penetration of devil spirits into the body, resulting in fever. Local healers should treat it. By examining the decision-making process in determining which disease symptoms are attributed to which system of beliefs, we can identify key players and the beliefs and values that influence the decision. When illness occurs in small children, the mothers and other cohabiting relatives are the first to assess the illness. Illness is most commonly identified by loss of appetite, the children's reluctance to play, and by dizziness. The parents and other relatives make the decision about the severity of the illness and whether local or Western treatment should be sought. The father, however, makes the final decision about treatment. The decision to label the illness as malaria or as a locally treatable disease is influenced by the distance to hospital and the cost of malaria treatment, which consists of medication and, often, blood transfusions for resulting anaemia. Once a decision has been made and appropriate treatment initiated, the illness will be

periodically re-evaluated and, based on perceived effectiveness, the decision will either be confirmed or the parents may change their labelling of the illness and seek treatment elsewhere. This process of decision-making is consistent with the process described by Brink (1977), in which the emphasis is on the role of the family in identifying the diagnosis and in selecting and evaluating possible treatment regimens.

A study of the health beliefs and behaviour related to dental care of the Ceará of the rural area of northeast Brazil (Nations & Nuto, 2002) demonstrates the conflicting explanatory models of the dentist and the population. The indigenous people have a long-established understanding of tooth decay and attribute it to *lagartas,* or tooth worms. This area of Brazil is economically depressed, and people survive on a diet high in starch and crude brown sugar. Sugar and sweetened foods are preferred for a number of reasons: to demonstrate affection, to "kill" hunger pains, to energize the malnourished and to appease the appetite of intestinal worms. The Ceará believe that if the tooth worms are not fed, they will become agitated and wander throughout the body in search of sweets. The *lagartas,* which grow strong and active from the sweets in the diet, are of lesser importance than these other considerations. It is only when the worm reaches the base of the tooth and pain occurs that action is taken. The action taken is aimed at removing the worm, not repairing the tooth. Remedies focus on sedating or killing the worm and include prayers to God and massaging the tooth or the cavity with corrosive products, such as coconut husk oil, battery acid, gasoline, and garlic. When all else fails, Western dental treatment is sought—not to repair the tooth but to have it removed, in hopes of also removing the tooth worm so that it cannot attack other teeth. Seeking Western dental services is otherwise avoided. There is a great deal of fear and anxiety associated with going to the dentist. This may be because the dentist and his tools are associated with the torture devices used in the past by military dictators. Nations and Nuto's study serves to demonstrate how beliefs about the cause of disease and past experiences can influence an individual's health care decision-making. This case study emphasizes the significance of the health beliefs on behaviour and decision-making. Here, as in the process outlined by Brink (1977), the decision concerning cure is made by the

individual and his or her family, not by the practitioner. Treatments that do not support the health beliefs are not considered credible.

In studying the health-seeking behaviour of Karachi women in Pakistan, Bhatti and Fikree (2002) found that a wide range of causes were attributed to reproductive track infections. These causes included ingestion of specific foods, inadequate hygiene, pregnancies, abortion and medical treatments such as tubal ligation. A number of health care providers were available to these women, and the researchers found that the average woman consulted between three and four providers during the course of her infection. The decision of which providers to choose was "based on recommendations from friends, relatives or social contacts, who had been successfully treated for vaginal discharge or any other gynaecological problem" (p.110). This supports Brink's (1977) conclusion that personal experience with a healer or hearsay evidence of trusted friends influences the decision regarding which healer to select. In the Karachi study (Bhatti & Fikree), the final decision was usually made by the woman's mother-in-law. The women accessed a variety of health providers: traditional birth attendants, traditional healers, homeopathic doctors, spiritual healers and allopathic doctors. Commonly the first health provider was an allopathic doctor. Women changed providers if they were not obtaining relief from the treatments, were referred by the provider to another, found treatment protocols cumbersome, or got access to a female provider. Bhatti and Fikree illustrate the family's control over the patient's health care delivery in conjunction with the social network, as well as the acceptance of multiple providers in dealing with health concerns.

The studies discussed in this chapter thus far demonstrate that cultural attitudes and beliefs determine how an illness is defined, and how and by whom it will be addressed. By increasing understanding of the process of health care decision-making, we gain insight into the sociocultural dynamics of the health and illness of a population. With this knowledge, illness and prevention can be addressed with respect to and consideration of the client's perspective, and should improve the quality of services and the effectiveness of treatments.

It has also been found that health promotion and prevention activities are influenced by culturally based beliefs and values. These health decisions include choices about lifestyle, such as what to eat, whether to smoke, what physical activities to participate in, and what preventative practices to engage in, as the following research illustrates.

Cassel (1977) identified the role of cultural beliefs and practices in shaping decisions about nutritional practices. The diet of the Zulu people of South Africa, in general, was found to be deficient in many areas because of limited resources and cultural attitudes towards certain foods. Community members were sceptical that their diet, which they identified as traditional, was a factor in their poor health and high mortality. Health care workers, in studying the traditional Zulu lifestyle, were able to identify that the existing Zulu diet had been altered from their traditional diet, and to re-introduce traditional practices, such as eating green vegetables, by facilitating family gardens. Other changes were not made as easily. While eggs were available as a source of protein, they were rarely eaten. "It was considered uneconomical to eat an egg that would later hatch and become a chicken; egg eating was regarded as a sign of greed; and finally eggs were thought by some people to make girls licentious" (p. 240). The strongest deterrent to consuming eggs was economic in origin. Techniques for improving egg yield led to a gradual increase in the consumption of eggs, and to the use of eggs as a commodity sold in local markets. The most culturally influenced dietary behaviour of the Zulu was the use of milk, especially important in prenatal women. In the Zulu culture, drinking milk is associated with very deep-seated beliefs and customs. Only members of the kin group of the head of a household could consume milk produced by that man's cattle. This meant that no one could drink milk produced by cattle owned by anyone outside his or her kin group. Women were further restricted in two ways. Menstruating and pregnant women were believed to exert an evil influence on cattle, and were therefore not allowed to come near cattle or to partake of milk if either menstruating or pregnant. Once married, a woman left her kin group and, unless her father gave her a gift of a cow, she could not partake of milk from her husband's kin group or accept milk from outside the kin group. Health care

workers were able to introduce milk from outside the kin group in the form of powdered milk. This was acceptable, since women drinking this milk would not affect the cattle of the Zulu. These minor yet culturally sensitive changes were shown to have a significant effect on the health of the Zulu involved. Infant mortality decreased from 276/1,000 to 96/1,000, pellagra and kwashiorkor all but disappeared, and there was an increase in birth weights by approximately two pounds. This case study indicates how culture and economics affect health behaviour and how health promotion, which incorporates these realities, can be successful.

The importance of incorporating local practices and culture into health promotion programmes has been advocated for many years, but the effects of doing so have seldom been demonstrated. A health promotion program aimed at decreasing diarrhoea in children of Bobo-Dioulasso in Burkina Faso, a small country in West Africa, endeavoured to incorporate local practices (Curtis et al., 2001). Local childcare practices identified mothers, older sisters, and maids as being the principal care-providers and therefore the primary targets for intervention. Through an investigation of local channels of communication accessible to the target population, radio, face-to-face communication and word of mouth were found to be the most effective means of communicating information about hygiene. Local beliefs linked hygiene to aesthetics and social status, but not to illness. The key motivating focus of the resulting hygiene promotion programme, therefore, was that hand-washing was seen to be socially and aesthetically desirable, with only secondary emphasis placed on the elimination of germs causing diarrhoea, which was not recognized by the target population. Results showed that by taking this culturally sensitive approach, there was a significant change in behaviour in hand-washing, both after using the latrine and after cleaning a child's bottom.

A study on breastfeeding practices in Gambia identified a number of cultural beliefs and practices that impeded the adoption of optimal breastfeeding practices (Semega-Janneh, Bøhler, Holm, Matheson, & Holmboe-Ottesen, 2001). Traditional colostrum was believed to be bad for a newborn and would cause diarrhoea, stomach pain, and fever. Colostrum's physical appearance, which is considered similar to pus,

was used to support this belief. Breastfeeding was supplemented by sugar water and, at times, formula and evaporated milk, with colostrum only being used when nothing else was available. The need to give infants water was based on the belief that since adults needed water to remain healthy, then infants did too. While health care workers were able to promote the practice of exclusive breastfeeding by illustrating that animals do not supplement their young with water and yet the young remained healthy, the beliefs about colostrum proved harder to influence and required further investigation.

All these studies demonstrate that in order to promote healthy lifestyle choices and preventive practices, knowledge and understanding of the cultural beliefs and practices is crucial. Successful health promotion is based on first identifying existing health practices, understanding the beliefs and values behind the practices and influencing these behaviours and related decision-making, by working within existing beliefs and practices.

In summary Brink (1977) and Twaddle (1979) both identified a decision-making process for illness management. Although the settings were very different, one in a Western urban setting (Twaddle) and the other in a rural African setting (Brink) their findings were similar. Their research suggests that decision-making is influenced by social, cultural, environmental and political factors. Similarly, theories and models of health behaviour (Fishbein & Ajzen, 1975; Becker et al., 1974; Becker et al., 1977; Cox, 1982; Pender, 1996; Plotnikoff & Higginbotham, 1998) suggest that health behaviours related to Health promotion/prevention decision-making is influenced by socio-cultural, environmental and political factors.

CHAPTER 3

KUGAARUK

The Inuit of Kugaaruk (Pelly Bay) (see Appendix E) are a sub-group of the Netsilingmiut (Netsilik Inuit-people of the seal) of the central Arctic region of Canada known as the Arviligjuaqmiut (those living in the area of Arviligjuaq, "place of the bowhead whales") (Metzger, 1999). The Arviligjuaqmiut were one of several distinct sub-groups of the Netsilingmiut identified by Rasmussen during the third Thule expedition (Rasmussen, 1976). While being culturally homogeneous, each group was defined by its own geographic identity.

Regional Environment

The traditional territory of the Arviligjuaqmiut (see Appendix F) "covered an area of approximately 12,000 square miles of which Pelly Bay was the centre" (Remie, 1983, p. 55). This area primarily consists of the Simpson Peninsula, and is located between Lord Major's Bay to the northwest and Committee Bay to the southeast (Rasmussen, 1976). The coast is predominately a "vast hilly region deeply cut by inlets and lined by innumerable islands" (Balikci, 1970, xvii). The Simpson Peninsula is "flat, representative of the typical mossy tundra topography. Countless lakes, ponds, and rivers are found everywhere, but harsh climate precludes much vegetation. There are no trees: instead, lichens, mosses, and various grass-like plants cover the tundra and hills, sometimes growing with creeping shrubs along the sheltered river beds" (Balikci, 1970, p. xvii).

The area surrounding Kugaaruk is classified as Arctic, in that the average temperature in January is -30^{0}C, while the average temperature in July is 10^{0}C (NWT Databook, 1990).

> July to September marks a time of rapid change. The sea ice melts and the tundra becomes a multi-coloured carpet of wildflowers. Migrating birds arrive from the South, including falcons, rough-legged hawks, snowy owls, seagulls, ravens, terns, jaegers, ptarmigans, cranes, ducks, geese and swans.... By the end of September, the ice starts to form again. (Metzger, 1999)

The Ethnographic Present

The first documented contact with the Arviligjuaqmiut is of the expedition of Sir John Ross, who anchored his ships nearby from 1830 to 1832. It was through this contact that wood and metals were introduced to the culture. Over the next several decades, additional expeditions had brief contact with the *Arviligjuaqmiut*, such as Rae in 1847 and 1854, Hall in 1864, and Schwatka in 1879 (Remie, 1983). Rasmmussen (1976) spent considerable time studying the *Netsilingmiut*, including the *Arviligjuaqmiut*, during the fifth Thule expedition from 1921 to 1924.

Cultural Characteristics

The *Netsilingmiut*, while sharing some cultural characteristics with other Inuit groups, have their own unique cultural characteristics. These cultural characteristics seem to be shared across all the sub-groups within the *Netsilingmiut*. Balikci (1970) describes the *Netsilingmiut* as having open relationships between the regional sub-groups, but avoiding contact with and mistrusting members of other Inuit groups.

Similar to other Inuit of the eastern Arctic, the language is Inuktitut. While there are some differences in dialect, this language is common to the Inuit from Gjoa Haven east to Baffin Island, and much of the northern Hudson Bay coast. Inuktitut was purely a verbal language, until church groups developed a written form. Its written form, Inuktitut, is a syllabic language with 15 symbols used in various configurations to represent the phonemes of the language (Edgecombe, 1998; Fletcher, 2004).

The *Netsilingmiut* trace both the paternal and maternal line. While predominantly a patriarchal (patrilineal and patrilocal) culture, maternal (matrilineal) relations are important and remain lifelong alliances. Traditionally, the nuclear family was the basic family unit and consisted of a father, mother and their children.

Sons would, on marrying, form their own nuclear family, but it was most common for them to remain with the extended family that comprised the nomadic groups of the Inuit. As the extended family size outgrew the resources, it divided into smaller groups. Upon marriage, a woman took her possessions, consisting of her tools

and her clothes, and joined her husband's household. These family groups were, however, fluid and flexible. A nuclear family would be considered part of several extended family groups on both maternal and paternal sides. An individual or nuclear family could decide to change the group in which they primarily resided (Rasmussen, 1976; Balikci, 1970).

Kinship terms are sensitive to the speaker, the specific family member being referred to, and the degree of relationship. An older sibling of the same sex was addressed as *angyayaq*, while siblings of the opposite sex were referred to differently, depending on the sex of the speaker: males referring to an older sister as *aliga* and females referring to an older brother as *ani*. Both genders share kinship terms for mother, father, cousin, aunts and uncles.

In addition to family relationships, there were formal relationships with individuals outside the family, which gave the external individual a formal relationship or partnership with family. *Nangminarit* were hunting partners who were a factor in determining the way in which game was shared. A man would have several partnerships with other hunters outside his immediate extended family. With each partnership came the sharing of a certain portion of any game acquired by a hunter. A seal was divided into 14 precise parts. The distribution of 12 of these parts would be to recognized hunting partners. Partnerships were usually for life, and were often inherited from father to son.

Other non-kin partnerships had social significance. There was a partnership between individuals with identical names, which was manifested in joking behaviour and the exchange of identical gifts when they met after a long separation. Joking, wrestling, and song partnerships developed between non-related individuals from outside the community. These partnerships acted as a way for outsiders to interact within the community without being viewed as a threat. With some partnerships came unique privileges such as wife-sharing.

Marriages were arranged. This was usually done either shortly after birth, or during the first few years of life. The boy's mother or grandmother usually initiated these arranged marriages. Marriage between first cousins was common and, in fact,

seemed desirable. Balikci (1970) attributes this to a distrust of strangers. After all, first cousins were usually well known to each other and to each other's families. Young men most often married by the age of 20, once they had acquired the necessary skills to support a family. Girls were usually 14–15 years old when they married. On the occasion that an individual reached marriageable age without a promised partner, they or their parents would intervene by seeking a willing, available mate. On occasion, the wives of other men were stolen or taken by force. This was likely in part due to the demographics of fewer women than men in the general population as a result of the practice of female infanticide.

Children further bonded the partnership of a husband and wife. Until the age of five or six years, girls and boys were raised primarily by their mothers. Once a boy reached six, his father took a more active role in his son's socialization. Boys would be given miniature tools and weapons to master, and by the age of 10 or 11, would be assisting their father in activities. In a similar manner, girls apprenticed under their mothers, although they had often assumed a helper status by their eighth year. Children learned through modeling, and negative behaviour was discouraged by teasing, mocking, and slighting.

Adoption was a common practice, and within the family unit, an adopted child held the same status as a biological child. Often, older grandparents would adopt grandchildren, ensuring that elders would be provided for in their old age. A couple with no sons would adopt, to ensure that there would be a new generation of hunters. The adoption of a female infant had a dual purpose: it provided a daughter who would grow up to help within the camp and, in many cases, saved the infant from infanticide.

Infanticide did occur among the *Netsilingmiut* and was more frequent with female infants. Rasmussen (1976) found that twice as many boys as girls survived infancy. This demographic imbalance equalized by adulthood, as boys were less likely to reach adulthood due to accidents. When possible, adoption was utilized as an alternative to infanticide. The practice of infanticide was a matter of survival, as it was sometimes necessary to reduce the number of non-food-producing people. Factors that

influenced infanticide included the size of the family, the successfulness of the hunting at that particular time, the order of birth and family dynamics (Balikci, 1970).

The tools of the *Netsilingmiut* were highly specialized and can be categorized into four technological complexes, based on the raw materials used: snow (ice), skin, bone, and stone (Balikci, 1970).

Snow was an important environmental element. It was the medium over which groups traveled for most of the year; it provided material from which dwellings were built; and it was the source of water for much of the year. During the winter months, holes in the sea ice provided the means of accessing seal and fish. Snow blocks were used to construct igloos, which were often multi-roomed complexes with central communal areas large enough for group activities. These dwellings were disposable and allowed the mobility necessary for survival in the Arctic. The need to utilize snow as a resource influenced the development of tools in the other complexes: bone knives to cut the stone blocks, sled runners, and ice drills, to name a few (Balikci, 1979; Birket-Smith, 1945).

The bone and stone complexes provided the raw materials to build tools, such as knives, drills, pots, lamps, needles, saws, spears, harpoons, and sleds. Many tools were designed for very specific purposes. There were a number of kinds of knives, each with a specific function: *pana* or snow knives were used for cutting the large blocks of snow for igloos; *ulus* or women's knifes were used to remove fat and fur from animal skins, so they could be used for various purposes; whittling and splitting knives were used to work bone into tools.

Skins provided the materials for clothing, bedding, tents, kayak hulls, and other equipment. Sealskins were also utilized to make harness lines, whips, water bags, floats, and in the construction of sleds. Caribou and seal pelts were predominantly used. The insulating properties of caribou were ideal for winter clothing. The durability and waterproof characteristic of sealskin made the pelt ideal for footwear, kayaks, and summer tents.

Leadership was based on family hierarchy. The "father was the recognized head of the family, responsible for all major decisions, essentially those involving

family location and movement. He did not interfere in his wife's sphere of activity; there she enjoyed considerable autonomy… A wife could successfully influence her husband in practically any decision. A husband very often took notice of his wife's desires" (Balikci, 1970, p. 109). A woman's sphere of activities consisted of those tasks done at home or in camp. These included butchering and distributing seal, cleaning fish, processing pelts, cooking, and caring for the wicks of the seal lamps. Many activities, such as hunting, were collective in nature, involving all appropriate members of the extended family. These activities were "supervised by the family headman. He was the father of adult sons or the elder brother, in general the eldest functioning male in the kinship group… *inhumataq*, or one who thinks" (Balikci, 1970, p. 116).

> The traditional spiritual beliefs of the *Netsilingmiut* were an integral part of everyday life. The natural and supernatural worlds overlapped and interacted in daily life. Skill in hunting, perseverance on the chase, and continuous endurance were qualities that helped to overcome the dangerous environment, but there were supernatural spirits behind the natural world which had to be contended with as well. It is a perilous visible world controlled by unreliable supernatural beings that is most characteristic of the *Netsilik* world view, a world of double danger. (Balikci, 1970, p. 212)

Spiritual activities occurred on two levels. At the individual and family level, there were numerous taboos, rituals, and the use of magic words. Magic words were passed from father to son, or purchased from a shaman. These magic words each had specific purpose.

> There were magic words for better hunting in strange lands, for help in caribou hunting, musk-ox and bear hunting, fishing arctic cod and salmon trout, to cure sickness and heal wounds, to facilitate birth, to make dogs hardy while chasing bears, to give boys strength in competitive games, etc. (Balikci, 1970, p. 217)

Taboos dealt with either "hunting activities and game animals" (Balikci, 1970, p. 218) or "critical phases of a person's life cycle (birth and death) and certain physiological functions such as menstruation" (Balikci, 1979, p. 218). Taboos had many social functions: they represented the duality of *Netsilingmiut* between winter/summer and land/sea. They provided a way to control the uncontrollable, such as death, birth, and the hunt. They provided a way to explain misfortune and illness, and they provided a mechanism to reinforce the belief in an omnipresent spiritual world.

Taboos related to hunting and game consisted of rules and rituals associated with how the carcass and its products were to be treated, and included rituals that demonstrated respect for the soul of the animal killed. Game was eaten raw or cooked in stews and soups. There were complex taboos about the separation of hunting, and using, land and sea game, often associated with the seasons.

Numerous taboos and rituals were associated with childbirth. These started with the onset of labour, when the woman was placed in isolation to deliver the child. Several rituals were associated with birth, relating to the cutting of the cord and cleaning of the child. For a month after the birth of a child, the woman remained separate from the rest of the group, although other women were allowed to visit her. For a year after the birth of a child, women observed dietary taboos such as eating only food caught by her husband and not eating raw meat (Rasmussen, 1976; Balikci, 1970). She could eat the soups and stews made from caribou or seal (depending on the season).

Death was also associated with numerous taboos and rituals. These prevented the soul of the deceased from turning into an evil spirit and causing misfortune. For a period of four to five days (depending on gender), it was believed that the soul remained in the body. During this period, household members followed strict work taboos relating to the activities of daily living. Following the mourning period, the body would be removed and either left on the ice in the winter or placed inland with stones positioned by the head and feet. Once this was done, it was believed that the soul departed for an after-world (Balikci, 1970).

Being healthy was considered a state of being in which the individual was integrated socially, temporally and spiritually with their environment (Therrien & Laugrand, 2001). Illness was considered to be the result of an element such as a lie or spirit inhabiting the body and interfering with this integration. In order for healing to occur, this element had to be removed from the body and the person had to be reintegrated into their social environment.

There were three possible after-worlds to which a soul could be relegated: *Agneriartarfik, Aglermuit,* and *Noqumuit. Agneriartarfik*, or the village in the sky, was a place of plentiful game, where life was happy and fun; a land of pleasure. Here one remained the age one was when one died, for all eternity. Men who were clever and energetic hunters, especially those who died violently, and women who had the courage to endure extensive tattooing, were allocated here. *Aglermuit* was located deep under the tundra. The seasons there were the reverse of those on earth and, like *Agneriartarfik*, life was good, and admission was based on cleverness, endurance, and being energetic. *Noqumuit* was located just below the tundra and was a place of perpetual hunger and hardship. This was where those who were idle, lazy, and apathetic in life ended up after death.

On occasion when, despite the taboos, rituals and magic words, misfortune or illness did occur, the intervention of an *angatkok*, or shaman, was necessary. *Angatkok* were individuals who were able to communicate directly with the spirit world through protective spirits (*tunraq)*. They were able, with the help of their *tunraq*, to vanquish the evil spirits, which cause misfortune and illness. They were also able to use their *tunraq* to influence game, the weather, and other activities of Netsilingmiut life. While *angatkok* could use their powers for the good of the group, they could also use their *tunraq* for personal gain and revenge against other individuals.

Culture Contact and Change

Over the past 100 years, the Inuit have undergone significant socio- economic change (Tester & Kulchyski, 1994; Fletcher, 2004). They have been forced to give up a traditional nomadic existence and adopt Western economics, religion, medicine, education and governance. Through the fur trade, they gradually became economically

dependent on trade and the products supplied by the trading posts. This resulted in economic distress when the price of furs fluctuated, resulting in the Canadian government providing relief services. An influx of missionaries brought Christianity and challenged many aspects of the Inuit culture, especially shamanism.

During and following the Second World War, southern interest in the north increased. During the war, military bases were established to provide support services to the war effort. In the 1950s the interest in the north continued, and the Distance Early Warning (DEW) Line site was built to monitor air traffic over the North Pole in response to the Cold War. In addition, the issue of Canada's sovereignty, which had been challenged for over 30 years, was again an issue for the Canadian government. This increased interest and expansion into the north resulted in further disruption of the Inuit society. Government initiatives established permanent settlements and Inuit were relocated to establish sovereignty and to serve as a labour force (i.e. building DEW Line sites and working in mines). With settlements came initiatives to provide education and health and social services. The Inuit became eligible for old-age-pensions and family allowances, which required people to be registered with the government and led to a further dependence on a money-based economy. With increased involvement in the north, the government became more involved in Inuit life. Cultural practices such as the custom of adoption were challenged. The Inuit were required to learn community governance and a justice system based on a Western model (Tester & Kulchyski, 1994).

With the increased contact with the south came new diseases. Miliary and Pulmonary Tuberculosis, measles and other communicable disease outbreaks became pandemic. The Canadian government responded by establishing doctors in selected settlements in the 1920s (Krepakevich & Harper, 1992). This process of medicalization of health services continued into the 1950s with Health and Welfare Canada. Medical Services ships visited communities in the eastern Arctic, assessing, treating disease and transferring people to hospitals in the south. Many who went south were never heard from again. In the late 1960s and 70s Nursing Stations were

established in communities to provide primary and community health care at the settlement level. These evolved into the Health Centres found in communities today.

In 1998 the Territory of Nunavut was established as part of a negotiated land claim with the Federal government. This land claim agreement also gave the Inuit title over areas of the territories with some mineral and wildlife rights and access to royalties on lands to which they did not hold title. The government of Nunavut is intent on providing Inuit with self-rule and providing culturally based programs and services. (Kulchyski, 1999; Nunavut Planning Commission, 2006)

Modern Inuit of Nunavut

Fifty percent of Canada's Inuit live in Nunavut, the remainder live in Quebec (21.2%), Newfoundland and Labrador (10.1%), Northwest Territories (8.7%) and in the rest of Canada (10.1%) (Statistics Canada, 2001a). Inuktitut, the official language of Nunavut, continues to be the first language of most Inuit (Statistics Canada, 2001b). Most people, however, are bilingual, with English as their second language (Statistics Canada, 2001c). CBC Radio broadcasts to the communities in Inuktitut several hours a day. Until 1992, several hours of television programming in Inuktitut, produced by the Inuit Broadcasting Corporation (IBC), were available through Canadian Broadcast Corporation North (CBC North). Since 1992, this program has been available through Television Northern Canada (TVNC) and provides native broadcasting for a number of aboriginal groups of Canada's northern regions. Today, television is available via cable or satellite. All the major networks of Canada and the USA are also available, as well as many specialized channels, including APTN. The local Co-op store rents out movies. School-aged children, through their school, have access to both computers and the Internet on a regular basis.

The government and a few private enterprises are the main sources of employment in Nunavut, and unemployment is high. According to the 2001 census, only 32% of individuals with income are employed full time and year round (Statistics Canada, 2001d). Governmental employment occurs at the Federal, Territorial and Hamlet level. Federal employment is limited and predominately located in the larger communities. At the Territorial level, there is employment through the various

government departments, such as health services and education institutions. Hamlets and towns are responsible for a number of services that provide employment, including water delivery, sewage and garbage removal, snow removal, housing allocation and maintenance, and fire and emergency services. Private enterprises in communities vary but may include stores, hotels, restaurants, and air carriers.

Policing is done by the Royal Canadian Mounted Police (RCMP), with at least one member in most communities. Additional members can be flown in from neighbouring communities when necessary. A local Justice of the Peace is able to handle judgements for many minor complaints, and, periodically, Territorial and Federal Courts are held by travelling court parties for more serious and capital crimes. While there is a holding cell in communities, prisoners are transferred to Territorial facilities while awaiting trial, as necessary.

Health care is available in all communities provided by nurses working in an advanced role in Community Health Centres. These nurses supply primary care, emergency care and community health care. When possible, nurses are hired on an indeterminate basis and stay one to three years on the average. When required, nurses are hired on a casual basis for anywhere from several weeks to several months. In larger Health Centres, there may also be a physician. Health Centre staff also includes, support staff, such as clerks, interpreters, housekeepers and janitors from the community. Some communities also have community health representatives, social workers and mental health workers.

Hamlet of Kugaaruk

The territory of the Arviligjuaqmiut falls within the Kitikmeot Region of Nunavut. Like other areas of the Canadian Arctic, the Arviligjuaqmiut were affected by the governmental policies that developed because of the defence facilities that were built in the Arctic following World War II. While not directly affected by the building of defence installations, the Arviligjuaqmiut were affected by related policies that resulted in the building of schools and the gradual movement of the population into permanent settlements.

The Hamlet of Kugaaruk is located along Canada's Arctic coast on the west side of the Simpson Peninsula, where the Kugaardjuk River enters St Peter's Bay (Appendix E). This is an area of rolling hills (NWT Databook, 1990). This location is approximately 1,300 kilometres northeast of Yellowknife, N.W.T., in the Kitikmeot Region of Nunavut. The community is rapidly growing, with a population of 605 (Statistics Canada, 2001e), a 22% increase from the 1996 population of 496 (Statistics Canada, 1996b). The demographics reflect a young and rapidly growing Inuit community. Statistics Canada (2001e) indicates that 54% are under the age of 20; 1.7% are over 65; 48% are female; 95% are Inuit; 43% are unemployed; and 48.1% have not completed high school and have no further education, while 22.3% have trades training and 19.2% have obtained education outside of high school (this would include any certificate course offered at the community level).

History

Although it would appear that the Netsilingmiut had limited direct contact with the outside world until the 1930s, there seems to have been ample indirect contact through the ongoing trading with the Inuit of Repulse Bay, who had regular contact with whalers. The first sustained contact was through the Roman Catholic Church, which founded a mission in Kugaaruk in 1935 and a trading post in 1937. In 1942, the RCMP first visited the mission at Kugaaruk when the RCMP ship, the St. Roche, was marooned in the ice on the west side of the Bootha Peninsula (Choque, 1985). The government established a presence in the 1950s by opening a school and a nursing station. In 1968, the Government of Canada established a permanent community in Kugaaruk by transporting in 32 prefabricated houses (Metzger, 1999). With this event, the Inuit slowly abandoned their nomadic way of life.

With the introduction of telecommunications technology in more recent years, indirect contact with southern Canada through the media has increased. Television became available in the early 1980s with one channel (CBC–the Canadian Broadcasting System), and by the mid-1990s more channels became available via cable. Today satellites provide the same programming available in southern Canada. Since the year 2000, the Internet has become available in the communities. These

communications developments have allowed the people of Kugaaruk access to information and to the influences of the outside world.

Community Infrastructure

The Hamlet is governed by an elected Mayor and Council, who are responsible for many of the local services. Water and sewage removal are provided by the Hamlet, with water delivered to homes by truck from surrounding lakes and streams, and sewage trucked to a nearby sewage lagoon. Power for the community is provided by a local government-run, diesel-generated power plant. Until the late 1990s, all supplies and goods were airlifted into the community, as the sea approach was not open to navigation. In recent years, with improved icebreakers, yearly sealifts of non-perishable goods, fuel and supplies have replaced these airlifts. The vast majority of Hamlet employees are Inuit.

A few homes are Inuit-owned as a result of a government initiative in the 1990s. This initiative involved financing and providing housing packages to eligible applicants to allow them to build their own homes. Financing was in the form of a low interest loan. The majority of homes are rented from the Nunavut Housing Corporation. Rent is based on market value and subsidized according to household income. In Kugaaruk, as with most Nunavut communities, housing is a major concern. Overcrowding is the norm. A three-bedroom home often houses three generations of a family. There are 20 families on the waiting list for a home of their own. In 2003, during the period of data collection, no new homes were built and in 2004 there were four to be completed.

Spirituality

The community has a Roman Catholic Church, with a priest and two Inuit adult servers. The priest is also responsible for two other communities, which he visits regularly. Services are held twice a week, Sunday morning and Wednesday evening. Sunday morning services are well attended, with an average of 200 people present. The adjacent large parish hall is often utilized for community meetings and as an overflow for the church. The divider between the chapel and parish hall can be

removed so that the church can accommodate the entire community, which is necessary at Christmas, Easter, for funerals and weddings.

The Inuit incorporate traditional and Christian spiritual beliefs in their everyday lives. Church is attended on a regular basis by between 100 and 150 people and at special service like Christmas; the majority of the population attends. I observed that all homes evidenced religious symbols to some degree. Most often this was a cross, a picture of Jesus and/or the Virgin Mary. While in most homes there were two or three religious pieces, in some there were numerous pieces. Similarly, I observed a number of religious rituals. All meetings were preceded by a prayer. Church services, while informal, included distinct rituals. At the end of the service two small crosses were brought to the front of the altar and children lined up to kiss one of them prior to leaving the church.

A strong belief in traditional Inuit spirituality co-exists with Christian beliefs. When an experienced hunter in another community went missing and died on a hunting trip, one of the possibilities that was discussed to explain how this could have happened to an experienced hunter was that a spirit had tricked the hunter, by appearing as wolverine and leading the hunter to his death. Elders expressed a belief that traditional deities still have influence in their lives today (d'Entremont & Houston, 2002).

Many traditional spiritual practices have, however, been abandoned. Shamanism is no longer practiced and magic words and songs have not been passed on. People related that their parents and/or grandparents had not wanted them to learn them and so they are lost. Taboos, such as those relating to childbirth and death are no longer practiced. Beliefs about the afterlife are predominately Christian. Some people expressed a belief that spirits could be malevolent after death, but being buried on consecrated ground was ample protection.

Relationships

Families remain predominantly patrilineal and patrilocal, although matrilineal relationships remain important. While some couples in their 40s are the product of arranged marriages, unions today are not usually arranged and, in many cases,

marriages are common-law. The custom of infant adoption continues to occur usually within the family group. When a couple cannot get their own home, they usually move in with the husband's family. Children are permitted a high level of autonomy and allowed to make decisions for themselves as long it does not put them in physical danger.

The traditional formal and informal relationships outside the family no longer hold importance. Hunting is done independently or with family members and game is no longer shared in the traditional manner. Today, sharing involves store-bought food, which was excluded from sharing in the past (personal communication, A. Balikci, June 10, 2003). The sharing of today is most often done between family members, with the unemployed asking for foods from employed relatives. A number of individuals who worked related that when they brought home groceries, their relatives would come, and they would need to give them groceries. As a result, they found it hard to make their pay checks last from payday to payday. In addition, individuals often used food instead of money to gamble. The built-in reciprocity and rules of sharing of the past no longer exist.

Traditional Activities

The Inuit continue to have a strong relationship with the land. Hunting and fishing, while no longer a source of income for all but a few who fish commercially, are important sources of caribou and arctic char (fish of the salmon family), which remain staples of the diet. Both women and men participate in fishing, although fishing weirs have been replaced by rods and nets. Today hunting for polar bear and narwhale is regulated so only a few are killed each year. A hunter's first successful hunt of either a polar bear or narwhale is a significant event, not only for that person but their family, and is considered a rite of passage. While hunting is predominantly a male activity, women are free to participate if they desire and their achievements are equally valued. During the research period several women occasionally went hunting; when one killed a polar bear, her family's excitement over the event was the same as when her brother had killed one earlier in the year.

Education

Basic education is available at the community level. There is a day care and a sporadic preschool program. The school in the community starts with kindergarten and recently added Grade 12, with the first graduating class in 2003. The school facilities include a library, gymnasium, computer and Internet access. Inuktitut is the first language of Kugaaruk and the language spoken in most homes. Most of the teachers at the school are *Qallunat* (non-Inuit), so instruction is predominantly in English, with Inuit teachers focusing on kindergarten and the lower grades. By the time children are of school age they have some English language skills learned from school-aged children and television. Attendance is poor by southern standards. Children are allowed to stay up late and are often too tired to get up in the morning and are allowed to stay home. Prior to the graduating class of 2004, only one person with a Grade 12 education was identified. The school dropout rate is very high (while no statistics are available for Kugaaruk the drop-out rate for Nunavut is 75% (Berger, 2006)). Parents stated that they had been hesitant to send their children out of town for high school, which was necessary prior to 2003. However, many individuals have obtained trade certificates (i.e. plumbing, carpentry) by attending Nunavut College in larger centers or attended certificate programs (i.e. basic accounting) at the local Nunavut College that were offered either on site or through Internet programs.

Nunavut Arctic College has a community learning centre and offers basic adult education programs from basic literacy to Grade 12 equivalencies. The centre consists of a classroom and computer access and the programs offered are based on student interest and instructor availability. The program, being offered during the course of this research was a basic skills course which taught math, English, Inuktitut literacy, and life skills. The program was attended by 8 women in their 20s. The spouse of a teacher was the instructor during my time in the community.

For recreation, there is an ice arena and a community centre with a gym, and teen dances are held regularly. Hockey is popular during the winter months and fishing during the summer. Social events are planned around special events such as

Christmas, Easter, Canada Day, and Nunavut Day. These involve church services, games and dances, which may go all night.

Commerce

The community has one general store, managed by the Koomiut Co-operative, which also manages the local Inukshuk Inn. The Inukshuk Inn has 8 double rooms and accommodates 16 guests. In the summer months they also operate a bunkhouse for construction workers, as needed. There is a dining room for guests and community members with reservations.

The prices for goods at the Co-operative are significantly higher than in southern regions of Canada, to offset the high operational costs. Most community members are Co-op members which entitles them to yearly dividends, based on how much they spend during the year. The more one spends, the greater the dividend, which ranged from $40 to $7,654 in 2004. These dividends were issued at an annual general meeting in mid-December and, in most cases, were used to buy Christmas presents.

Fishing and hunting continue to be central to the Inuit diet with char and caribou being the dietary staples. Dried char was a staple at many community functions that included food.

The community has a two-man RCMP detachment and during the research period, one of the members was Inuit. The office is a small trailer with a file room, desks and a holding cell. The Health Centre was staffed with two nurses, a Community Health Representative (CHR), a social worker, a clerk-interpreter, a janitor a part-time housekeeper and four part-time home care workers. Occasionally there would be a third nurse for short periods of time.

Health Practices

Use of traditional herbal remedies was not observed, and the only remedy that any of the interviewed elders could remember was using dog urine to treat a cold. As Luke remembered "They would use the urine of the oldest dog they could find and take it (orally) as medicine." One elder thought he remembered a plant being used to make tea, but was not sure what it had been for. Today self-treatment consists

primarily of over-the-counter drugs available at the Co-op store. These included cold preparations. Breathing in steam or using a humidifier were also mentioned by some individuals.

History of Disease

A history of disease is important in order to understand how people today view illness. Infectious diseases are known to have caused epidemics since the 1920s. One of the earliest epidemics in the Central Arctic was miliary tuberculosis in the 1920s (Krepakevich & Harper, 1992). After the Second World War, cases of both miliary and pulmonary tuberculosis from Kugaaruk were transported to the Charles Camsell Sanatorium in Edmonton. Those who did not die were away from their families for prolonged periods, sometime years. Up until the 1980s, when improved chemotherapies were developed, this was the preferred management for TB. Since the 1980s, treatment has required a two-week stay in hospital where treatment is initiated after which the patients can be treated in their home community. Betty, who spent several years at the sanatorium in the 1970s as a child, recalled being lonely and losing her native language. She also spoke of learning to sew and going to school and visiting with other Inuit patients. No one interviewed was aware of an active TB case in the last 10 years, although they were aware of cases in other communities in the region.

While the rest of Canada identifies 1918 as being the year of the last major influenza pandemic, the Inuit remember the spring of 1960. While there have been flu outbreaks since then, nothing has been as severe. The outbreak that year affected almost everyone, and killed 10–15% of the population (A. Balikci, personal communication, June 10, 2003). As a result, all adults in Kugaaruk can name at least one immediate family member who died from influenza—in some cases, multiple family members. Many are buried out on the land, close to where they were living in camps in the surrounding area, and others are buried in a mass gravesite by the original church. This epidemic has had the greatest impact on the community.

Up until the late 1980s, Haemophilus B. Influenza infections were common in preschool children in Canada. In southern Canada, the presentation was predominantly epiglittitis, while in the Inuit, the presentation was predominantly meningitis. Both are

serious and life-threatening; however, meningitis has the added risk of life-long brain damage and the resulting sequela. In addition, the incidence of infections was higher in the Inuit population (Hammond et al., 1988). While the vast majority of Inuit will know of someone who had a child who had meningitis, many people in the south are not even aware of epiglottitis, let alone know anyone who had it. Although immunization against meningitis has removed this threat, the memory lingers on and influences decision-making regarding sick infants with high fevers.

Annually, bronchiolitis and Respiratory Syncytial Virus (RSV) infections affect infants throughout Canada; however, the incidence and morbidity are more severe among the Inuit. In southern Canada, RSV is a common cause of bronchiolitis, with 2% of infected children ill enough to require hospitalization (Health Canada, 2003). In contrast, in the year during which these data were collected, over a five-week period, 90% of the 36 children in Kugaaruk under the age of two contracted bronchiolitis, and 75% of those children required hospitalization due to RSV. This was considered a typical year. Historically these infections occur in the late spring and early summer, and the outbreak lasts four to six weeks.

Health Concerns

A number of territorial health concerns are pervasive in the Inuit population including Kugaaruk. These include environmental contaminants, suicide, substance abuse, and the social problems associated with substance abuse, such as family violence and crime.

Suicide rates in Nunavut are much higher than the rest of Canada: an average of 324/100,000 per year compared to 70/100,000 for Canada as a whole (Nunavut Department of Health and Social Services, 2003a). The victims of suicide are predominantly young men and this represents a serious mental health problem. There have been no recent successful suicides in Kugaaruk: however, because of the history of suicide in the community and the knowledge of suicides in other communities, it was a concern.

Substance abuse, mainly alcohol and marijuana, was a major concern for the community. Kugaaruk is a "dry community," which means that a bylaw prohibits

substances being brought into or manufactured in the community. Despite this, people smuggle alcohol and drugs into the community, and the consumption in certain sectors of the population, especially young adults, is quite high. Associated with the substance abuse are related social problems: family abuse, and violent crimes. Of the 12 cases brought before the Territorial Court in 2003, 11 were alcohol-related. These included spousal abuse, sexual assault, and assault. Alcohol was the catalyst in all these cases. One man, charged with molesting his adolescent stepdaughter, pleaded guilty, stating that although he had no memory of the event because he had been drinking, he had no reason to believe his stepdaughter was lying, so he must have done it.

Contaminants

The rates of contaminants in the Arctic food chain are of concern. The Inuit continue to depend on hunting and fishing for food. The levels of environmental contaminants, such as DDT and PCB, in maternal blood in Canadian Inuit are higher than in the Caucasian population of Canada (Van Oostdam & Tremblay, 2003). Contaminants are not carcinogenic, but have been linked to other health risks such as birth defects. In Kugaaruk, contaminants in the food chain did not appear to be of great concern. Other environmental concerns were expressed, however. Harvey, a 50-year-old community leader, questioned whether the chemicals in the cardboard that was commonly used as a cutting surface when cutting and eating raw meats could cause illness. An elder remarked that there was more pollution than in the past and attributed it to all the motor vehicles that were used. While there were no cars in the community, there were many trucks used by businesses as well as the Hamlet for transportation of equipment and workers. In addition, there were tank trucks for water and sewage transportation and ploughs and heavy equipment vehicles for road maintenance. All terrain vehicles (ATVs) and snowmobiles were used for personal use, and almost every family had at least one of each. During the fall of 2003, concern was expressed about the effects of global warming. The fall had been warmer than usual, which resulted in more snow than usual before the ice had had a chance to freeze well, leaving the ice unstable. This made traveling by snowmobile more

difficult and was blamed for the drowning of three children who had been playing on the ice on a pond in a nearby community.

The Inuit of Kugaaruk, like Inuit across the north, have been rapidly thrust into the 21st century. Over the course of 80 years they have gone from a nomadic to a space-age society. They have gone from self governance to being ruled by the Federal government to self-rule. They have maintained a distinct cultural identity and are committed to strengthening this identity. With these changes have come disruptions to the health and well-being of the people and their social network.

CHAPTER 4

FORMAL HEALTH CARE DELIVERY SYSTEM IN KUGAARUK

The formal health care system provided to the Inuit of Nunavut is based on the Western medical model. As a result, health behaviours and illness are evaluated by biomedical professionals based on the biomedical model, with little or no attention to Inuit cultural beliefs. These cultural beliefs, however, influence the worldview of the Inuit, as well as their attitudes and behaviours relating to health and illness. To what do the Inuit attribute good health and illness? How do they classify illnesses? What are their expectations for treatment? Whom do they go to with health concerns, and why? These and other questions underlay the development of this research project.

The health care system in most Inuit communities consists of a Health Centre staffed by nurses and support staff. Services consist of primary care, emergency services and community health services. The Health Centres have clinic hours daily during the week, with after-hours and weekend services as required and provided by "on call" nurses. Primary care services are consistent with the services provided by general practitioners in other locations. Part of each day, usually the morning, is dedicated to "sick clinics" for individuals with health problems; during these hours, individuals can gain access to primary care services. Community health clinics are held during the rest of the day and include Well Child Clinics, prenatal clinics, chronic disease clinics and Well Woman Clinics. Additional community health programs are available as needed. Emergency services are provided at all times. Periodically, a regional physician visits the community to see patients referred by the nurses, or patients who require medical follow-up. In between physician visits, nurses consult with regional physicians by phone and, if necessary, refer patients to the nearest hospital. Depending on the acuity and nature of the medical problem, patients can be air-transported for medical assessment and intervention by either scheduled air flights or air ambulance. Specialized medical services are provided through regular visits to the community by the specialist or by referral of the patient to a larger centre where services are available. All services provided through the formalized health care system are part of the Territorial Health Care program and have no cost to the consumer.

Prescription drugs, medical supplies, dental and vision care are provided free of charge to the Inuit through the Federal Non-insured Health Benefits Program. A limited number of over-the-counter drugs, such as acetaminophen, are available at the Health Centre for clinic use and for patients who cannot afford to buy them at the local store.

The Kugaaruk Health Centre

The Health Centre in Kugaaruk is a two-story building located in the centre of the community. The first floor contains the clinic, and the second floor consists of four apartments for the nurses and other health and social services staff. I was in one of these apartments during the time I lived in Kugaaruk.

One enters the Health Centre into the waiting room, which is located in the middle of the building. The waiting room area consists of two wooden benches, a wall-mounted TV, two large bulletin boards and a card table, on which health-related materials are placed. On slow days, people came in and went in quickly to see the nurse, but on most days, there were a number of people waiting to be seen, and took this time to visit with each other. People know each other, and are often related, so interactions were very social, centering not just on why they were at the Health Centre but also on "catching up" with each other. There were no toys in the waiting room (an infection control measure), so children ran around the room and sometimes the hallway. The television was always on and during sick clinic was often tuned to children's programming by parents. There were, however, times when clients purposely tuned it to popular programs. Popular programs included "The Price is Right," "Oprah," soap operas and sports.

In the north end of the building are the clinic rooms. These consist of three examination rooms, an emergency room, an X-ray/lab room and an in-patient room with a bed and crib. The south end of the building provides both office and program space. The offices for the Nurse-in-charge, CHR (Community Health Representative) and social worker are here. Home care records are housed here and office space for the program is provided when required. The Health Centre was not built to accommodate

all these services, and as a result, the public health teaching room has become office space and storage areas have had to be utilized.

Sick Clinic

For a community of between 600 and 700 people, the sick clinic at the Health Centre is extremely busy. There are 12 sick clinic appointments per day (60 per week and 3,120 yearly) and seldom during my year in Kugaaruk were there unutilized appointments. When appointments were cancelled or no-shows occurred, they were filled by call-ins. In addition, numerous people were seen outside regular appointment times each day.

As soon as the clinic opened in the morning, the phone started to ring with people wanting to have themselves or a family member seen by the nurse for illness. Openings in the morning sick clinic, if there were any, quickly filled up, and then appointments were made for later in the week. Frequently people asked to be seen that day anyway and at this point the calls were transferred to a nurse, who then screened the caller further to determine if he or she could wait to be seen until the next scheduled opening, or if the individual should be booked in somewhere else during the day. If deemed necessary, he or she was booked into the late afternoon, following the public health clinics. The nurses seemed to know the clients well and the decision to see them was based primarily on the problem present, the age of the sick person and, on occasion, how likely they were to have to see the patient after-hours if not seen during the day.

Clinic utilization. While visiting with people in the waiting room, I was able to establish that most people came for minor illnesses, colds, fevers, draining ears, coughs, and diarrhoea. The vast majority were sick children under the age of five. A common presentation was that the child had been sick with a symptom starting the day before or during the night, so the child was brought in for the nurse to see. If it was a repeat visit, it would be either because the nurse had requested it or that the symptom had not improved. Often there was only a short period between initial visits and a parent-initiated follow-up visit, because of the treatment's failure to resolve the

symptom. The parent-initiated follow-up visits were more frequent among young mothers who had little formal education.

School-aged children and adults were usually seeking care for one of two reasons. The most common was that they did not feel well enough to go to school/work, and at least part of their reason for seeing the nurse was to get a certificate of illness for the school or employer. For these individuals, the reason for seeking care was not so much to seek health care as to get documentation of the illness for employers. This documentation was necessary for many employers if employees missed work for their own or their children's illness. The second reason for adults and children seeking health care was related to unusual symptoms, persistent symptoms, symptoms associated with a known, more serious illness or a significant change in behaviour. In these cases, the individuals had a sense that something was wrong beyond a common illness. The severity and concern over the presenting problem varied greatly. Frank, a 68-year-old man, had a history of breathing problems with an episodic cough and sputum. On one occasion when he noticed his voice becoming hoarse from coughing and his feet were swelling, he sought treatment. He was medivaced to Yellowknife for heart problems.

Public Health Clinics

Afternoons at the Health Centre focused on administrative activities and specialty clinics. Administrative activities included ordering drugs and supplies, cleaning, in-services, and program planning. The specialty clinics, provided weekly, were prenatal, Well Woman, Well Man, Well Child and chronic disease. Specialty clinics were by appointment and usually initiated by the staff of the Health Centre, based on clinic-specific criteria.

Prenatal clinics were organized so that women were seen regularly throughout their pregnancies, and the frequency of visits was based on the stage and nature of pregnancy. In the spring of my time in Kugaaruk, there was an active community-based Prenatal Nutrition Program, funded by a federal Health Canada initiative. Part of this program afforded opportunities for the local program coordinator to provide healthy snacks to women attending the prenatal clinic. These were distributed to the

women in the waiting room area and prenatal videos were shown on the television. These snacks consisted of fruit, cheese and crackers, and juice. Whether or not the prenatal women ate the snack themselves depended on whether or not they were attending the clinic by themselves or with a child. If accompanied by a child, they would either share with the child or give the snack to the child. If shared, the larger portion usually went to the child. Mothers stated they wished to provide the child with a treat or were responding to the child's request for a snack. Approximately every three months, an OBS/GYN specialist and ultrasound technician would visit for several hours. On these visits, prenatal women and women identified by the nurses or visiting physician as having significant GYN problems had priority, followed by women with minor GYN complaints. The team would charter in by plane, see patients and then, several hours later, charter out. Although the visit was planned and known about in advance, the exact time of arrival was not known. The patients who were to be seen would be notified of the day on which the team was coming, and told that they needed to be available so they could be called as soon as the expected time of arrival was known. This was estimated from a phone call from the nurse in the previous community, who would call to say they had just left the Health Centre there. On one occasion, weather prevented the team from going into one community, so they came to Kugaaruk the day before expected, with only an hour's warning. Several people could not be contacted, and therefore missed appointments.

At 36 weeks' gestation, women flew the 1,300 kilometers to Yellowknife to have their babies, with an anticipated wait of four weeks away from home. While in Yellowknife, they stayed at a boarding home run by the Nunavut Department of Health and Social Services for Inuit Outpatients from Nunavut. Because of the distance, cost of travel and accommodations, family members were seldom able to travel and attend births. Usually, however, someone else would also be out for medical reasons, so they always knew someone in Yellowknife.

Well Woman and Well Man Clinics were run simultaneously. These clinics are used to monitor general health status and to screen as appropriate for high-risk conditions such as common cancers, diabetes, hypertension and sexually transmitted

infections (STIs). While Well Woman Clinics are well established and had high attendance, the Well Man Clinics had been established recently and were poorly attended. Women are used to being called in for Well Woman check-ups and most took advantage of the services. While I was there, the nurses made a concerted effort to get men interested in Well Man Clinics. Since men were not used to these clinics, they were approached slightly differently. Instead of calling men in, the nurses carried out an education information blitz and then approached men who were in the Health Centre for other reasons, getting them to make appointments to be checked. Several men who knew the Health Centre nurses socially did make appointments and have check-ups, but for the most part, men did not attend these clinics. Most men did not see a need to see the nurse unless they were sick.

Well Child Clinics consist of programs for pre-school children. Children under the age of five make up 17% of the population (Statistics Canada, 2001e), so this was always a busy clinic. This clinic is used to monitor growth and development, provide immunization and screen for common health problems that might affect general health. I observed attendance rates to be high and the nurses indicated the immunization rates of children are high. The nutritional status of newborns is assessed weekly and infants and young children are seen in conjunction with routine immunizations. Children with risk factors or chronic diseases are seen more frequently, as necessary. Ben, an 18-month-old with a long history of failure to thrive, was seen on a weekly basis for weight check and to give support to his mother, Pam, in her attempts to find foods he would eat.

Chronic disease clinics have two main components: 1) surveillance of chronic conditions, and 2) the monitoring and refilling of medications. Patients with chronic disease were regularly followed up on, based on the nature of the disease. Follow-up varied widely, depending on the severity of the condition, stability of the condition and the medications the patients were on. Some, such as Sarah, a 30-year-old who had had a heart valve replacement, were seen several times a week to monitor blood work in order to adjust medications. Others, such as Ken, a 50-year-old with previous high cholesterol, were seen yearly to screen for diabetes, hypertension and hyperlipidemia.

Many, however, were seen on a more regular basis. These included most elders who were followed up for chronic conditions such as COPD (Chronic Obstructive Pulmonary Disease), and arthritis.

Pharmacy Services

The Health Centre includes a small pharmacy for the dispensing of prescription drugs. A Regional Formulary provides direction on what drugs may be ordered and guidelines for which drugs the nurses can dispense independently and which require a doctor's order. Only essential over-the-counter medication, such as mild analgesics, antipyretics, antiemetics and antihistamines, were stocked in the pharmacy. The policy was that nurses were to encourage people to purchase over-the-counter drugs at the local store and only dispense them from the pharmacy when seeing patients after-hours or for a patient-specific reason, such as giving acetaminophen when seeing someone with strep throat for pain and fever. Vitamins were stocked for prenatal women, and infants. The nurses overlooked this policy when patients indicated they could not afford to purchase drugs and when the medication was for an infant or child, especially when the drug was an antipyretic such as acetaminophen.

There is no drug store in Kugaaruk, so patient-specific prescribed medications are sent to the Health Centre from a pharmacy in Yellowknife and then distributed to patients. Because it can take considerable time from when a medication is ordered or reordered until it arrives in the community, the nurses try to keep a supply of the patient's medication at the Health Centre, so if the patient runs out, they have some back-up medication available. To do this, they do not distribute the entire supply of a prescription to the patient. In addition, with patients who are on multiple prescriptions and/or have difficulty remembering to take medications, the nurses fill dosettes for the medication rather than distributing the supply, similar to the way it is done for home care patients in the south. As a result, on any given Chronic Disease Clinic day, distributing medications is a time-consuming task. In addition, reordering medications, if needed, is a complex and lengthy process that the nurses and, at times, the patients find frustrating. If the patient requires a refill on his or her prescriptions, the nurse circles the drug on a computer printout. If there are refills on the prescription, the

pharmacy will send the drug the next week. If there are no refills left, the nurse fills out a prescription form, which is faxed to one of the regional physicians to sign, and then faxed on to the pharmacy so that it can be filled. The originals of the signed prescriptions are mailed back to the Health Centre for the clinic records. Sometimes it takes several attempts before the signed prescriptions get to the pharmacy. To further complicate things, some drugs are not automatically covered by insured services, and a special request form must be filled in yearly and approved by Health Canada before the prescription can be refilled. As a result, many times there is a delay in patient medication reaching the community. Usually these delays are brief, but on occasion, it will take up to a month.

In my observations, the nurses were constantly frustrated by the process, both because it was labour-intensive and because it often did not work, and they were the ones who had to deal with the results. When patients were on common medications, the nurses were often able to break the rules and dispense medication from stock supplies, use medications of patients who were no longer on the medications or, as a last resort, "borrow" from other patients. However, on the occasions when they could not do this, the patients would have to go without, which sometimes resulted in an exacerbation of their chronic condition. Most people, while frustrated, were accepting when they were told their medications were not available and that they would have to do without. If an exacerbation of their condition did occur, they willingly tried less effective treatments until their medications did arrive.

Jerome, an elderly man, demonstrated this. He was on gout medication that required a new prescription. The nurses faxed the prescription to the doctor for signature, but for some reason it was not received by the pharmacy, so the following week, his medication was not in the drug order. By that time the nurse had a copy of the signed prescription and faxed it on to the pharmacy. The next week, when the drug order arrived, his medication was not included, although there was a note stating that they required an authorization from Health Canada, as this was a non-insured drug. The nurses filled out the required paper and faxed it on to the doctor for signature. He then faxed the form on to Health Canada, and two weeks later, the drug arrived. While

Jerome understood this process, it was frustrating, and a hardship for him. Before the drug arrived, his gout flared up again. He was hesitant to take the alternative medication that was available, as the doctor had discontinued it some time ago because of another chronic condition he had. By the end of the second week, with the reassurance from the nurse that she had checked with the doctor and that taking the medication for a brief period would not be a problem, he decided to take the alternative medication until his medication arrived in order to control the pain.

Occasionally people's frustration turned to anger, which was directed toward the nurses. They felt that if the nurses wanted to, they could fix the problem.

Mental Health Services

Mental health services were nominal. In acute situations such as attempted suicide the nurses simply reported the crises they had just dealt with. They did little counselling themselves but rather arranged for referrals either when the psychologist visited the community or by arranging for the client to be seen in Yellowknife. Once the psychologist had seen the client, the client would continue to have ad hoc telephone sessions with the psychologist between community visits. People were encouraged to utilize elders, and the community wellness worker, who does basic counselling, at other times. When there was a social worker in the community, he/she would do some family and court-directed counselling.

Medically diagnosed mental disorders, such as depression, and anxiety were treated as medical disorders and treated pharmacologically. Services for mental health problems, such as substance abuse, family violence, and posttraumatic stress disorder were limited and involved the nurses only when a crisis occurred, or if someone asked for assistance. Few resources were available to help people with ongoing problems. Ted, a young man in his 20s, recognized he had a problem with alcohol that interfered with his ability to keep a job. He sought assistance from the nurses and social worker for this problem. Although they gave him advice and tried to get him enrolled in a treatment program, there were none within Nunavut and they could not get approval for treatment outside the territory. While they continued to support his attempt to stop drinking he was not able to do so.

There were attempts to increase awareness of mental health issues such as substance abuse and family violence through health promotion activities. These included radio programs, presentations at the high school and a bulletin board presentation at the Health Centre. The nurses participated in community meetings, such as health committee meetings, and a community meeting on gas-sniffing and substance abuse.

Emergency Care

Emergencies were dealt with as they occurred. With only two nurses, even a minor emergency, such as someone requiring sutures, could have a significant effect on clinic operations and therefore on people waiting to be seen. When minor emergencies occurred, they were usually worked around and clinics, although behind schedule, did finish. On those occasions when the nature of the emergency was more severe, clinics were either postponed or cancelled. Emergencies were infrequent but included injuries such as a Ski-Doo accident with a scalp laceration requiring over 100 sutures; a compound fracture of the arm; and medical conditions such as acute congestive heart failure.

With regard to the sick clinic, people were either seen after the emergency or asked to come back later that day or the next, depending on the nature and severity of their illness. For the most part, people understood. They knew the person who had the emergency, and if this was not a family member, they all had family members who had required emergency care at some time.

Following emergencies, family members would gather at the Health Centre. They would collect in the waiting room, watch television, visit and support the patient, and on occasion assist the nurses by making calls, and stay with the patient so the nurse could contact the doctor, arrange evacuation, do tests and prepare treatment. In the cases where a prolonged stay or evacuation was necessary, once the patient was stable, family members would stay with the patient so that the nurse could return to other patients or do other things, and were therefore responsible for monitoring general status.

After-hours Calls

Outside regular clinic hours, people who wanted to be seen or had a concern called the "nurse on call," who decided what action to take. In my observation, the actions taken seemed to be based not only on the severity of the illness or concern, but also on the knowledge of the patient, their ongoing health, the time until the next sick clinic, and family dynamics. Becky, an 18-year-old woman, was seen for a strep throat on a Saturday evening as the next regular clinic was not until Monday and that was deemed by the nurse on call to be longer than was reasonable for Becky to wait.

The most common reason for requesting after-hours care was that an infant or child was sick. The two most common complaints were respiratory symptoms for infants and diarrhoea or vomiting. In most cases, children under two years of age are seen after-hours to do a basic initial assessment and treat if necessary. In the case of diarrhea, this protocol allows the nurse to get a baseline weight in order to monitor hydration.

Home Care

At times, care was provided in the home by either the nurse or a home-care worker. Three part-time home-care workers in the community provided supportive services, such as cleaning, respite care, and other non-medical services in the home. During the period I was in Kugaaruk, there was little health need for home care nursing services, as there was only one bedridden person for a brief period, so the program was used to provide additional support for elders and chronically ill people. These services included cleaning and respite for other family members.

During this period, one terminally ill individual required additional support as his illness progressed. This was done in consultation with the patient and family, who chose to use minimal service other than physical resources, such as a wheelchair and commode chair, and the nurse visiting on a regular and ad hoc basis. The nurses, however, did make regular visits to the home, in addition to visiting whenever the family requested.

Outpatient Services

At times people, while ill enough to require outpatient treatment, were well and stable enough to be treated and/or monitored on an ongoing basis. These people would either return to the clinic at set times during the day for assessment and treatment, or carry out treatments at home and come in at set times during the day for assessment. The most common outpatient treatments were inhalation treatments with bronchodilators and corticosteroid solutions. Most commonly, these treatments were for infants with wheezing secondary to respiratory infections. Respiratory infections are common in Inuit infant and toddlers. They are most often viral. The most common serious respiratory illness in Inuit Infants is bronchiolitis, which is often complicated by Respiratory Syncytial Virus (RSV) and/or pneumonia.

Infants with RSV often develop reactive airway disease in response to the infection, which may persist for years. Treatment of both the acute illness and resulting reactive airway disease is to treat the symptoms, such as fever and bronchospasm. Except in cases of respiratory distress, hospitalization is not necessary. The decision to send a child out to hospital is based on symptoms, especially respiratory status, as indicated by respiratory rate, pulse, O_2 saturation and pattern of breathing (evidence of laboured breathing, such as in-drawing or nasal flaring).

Parents varied in their acceptance of these treatments. Some had been through the process on previous occasions, either with this child or with another one, and had seen evidence of its effectiveness. Others did not see any benefit to the treatments and were, to varying degrees, dissatisfied with the care their child was receiving, wanting their child sent to the hospital in Yellowknife.

Diagnostic Services

A few diagnostic tests can be carried out by the nurse or the support staff in the Health Centre. The caretaker at the Health Centre has taken a basic X-ray course and can take chest and limb X-rays. These are then sent to Yellowknife to be read. The delay in getting X-rays read was of some concern when dealing with chest infections. The nurses exhibited their resourcefulness by using their own camera to take digital photos of the X-rays and e-mailing them to physicians when they wanted immediate

feedback. More advanced radiographic procedures require patients to leave the community.

The nurses do electrocardiograms (ECGs), which are faxed to physicians. Basic blood tests, such as haemoglobin, white blood counts, glucose levels, erythrocyte sedimentation rates (ESRs), urinalysis, and urine cultures, are done by the nurses as necessary. All other lab work is sent out to labs in either Yellowknife or Iqaluit.

Physician Services

Regional physicians based in either Kugluktuk or Cambridge Bay provide general practitioner services, and these physicians visit the community periodically to hold clinics, primarily seeing people referred to them by the nurse. Community members expressed concern and some frustration because of the infrequency of the visits. A number of specialists visit the community on a regular basis: Obstetrics/Gynecology (OBS/GYN), Ears, Eyes, Nose and Throat (EENT), Pediatrics, Dentistry and Mental Health. These clinics, while welcome, were an added stressor for the nurses and, at times, the patients.

While all of these clinics were busy, some were hectic, and both the patients and nurses were affected. The first GYN clinic I witnessed was one of these. This clinic consisted of a gynecologist and general practitioner who used a portable ultrasound to do prenatal ultrasounds. The team was in the community for only a few hours, and the exact time of their arrival was not known until an hour before their arrival. This meant that the nurses and the women needing to see the doctor or have an ultrasound were on stand-by. The clinic, when it did occur, was after regular clinic hours, which meant the nurses worked overtime.

The infrequency of physician visits often prolonged the process of diagnosis and treatment. A person would see a doctor, who ordered tests, and then have to wait until the next visit to have the doctor order additional tests. This was especially frustrating for people seeing specialists who only visited two or three times a year.

Medivacs

On the occasions that a person is sick enough to require hospitalization, they are transported by a medical flight or medivac to the hospital in Yellowknife, 1,500

kilometres away. A specially equipped plane and flight nurse(s) provide this service. These flights originate in either Cambridge Bay or Yellowknife and are dependent on the weather in all communities involved. At a minimum, it takes an hour for a medivac plane to reach Kugaaruk, and another one and a half hours to get the patient to Yellowknife. However, due to weather and availability of crew, it can be much longer. During the bronchiolitis season that I observed, when there were frequent medivacs around the region, the nurses kept an infant in the Health Centre for over 24 hours waiting for a plane, because of a combination of bad weather and the flight crews having flown the maximum number of hours allowed by Transport Canada.

Health Promotion

Health promotion at the community level took place in a number of ways. The bulletin boards in the waiting room of the Health Centre were utilized to display health promotion information. Every four to six weeks the themes changed. The information was focused on high-risk behaviours such as smoking, drug use, suicide, dental care, and sexually transmitted diseases. The Community Health Representative regularly made presentations at the school and on the radio related to health promotion. These presentation included topics such as safe sex, STIs (Sexually Transmitted Infections), smoking cessation and nutrition. The nurses and Community Health Representative held educational sessions on infant care, infant feeding and normal discomforts, such as teething. There were a number of federally funded health promotion initiatives which, while not directly associated with the Health Centre, were supported by the nurses, such as food mail and the Prenatal Nutrition Program.

A food mail program is an initiative to encourage the store to stock affordable, fresh produce and dairy products by subsidizing the freight costs. Part of this program was for a local worker to monitor the prices and quality of the produce and to promote the use of these foods through activities such as demonstrations on food preparation. Unfortunately, there was minimal training for this worker, and the demonstrations were minimal. Even though there were transportation problems, which negatively impacted the quality of the produce, the price of produce was maintained at a level where most people could afford some fresh produce and/or dairy, to some degree.

A Federal-funded prenatal nutrition program provided the opportunity to assemble prenatal and breastfeeding new mothers to a cooking class. These occurred weekly during the winter, spring and fall. In the spring, the program also included weekly prenatal information sessions and the provision of nutritional snacks and information at the Health Centre during prenatal clinic. This program was operated by the Hamlet, funded by the Federal Prenatal Nutrition Program and was conducted by Inuit workers. Over the summer, the trained worker moved to another community and the newly hired worker lacked the training to continue with the classes, although the cooking classes continued until Christmas.

The Hamlet employed an Inuit community wellness worker who was responsible for developing health promotion activities in the community. This included identifying possible sources of funding and developing funding proposals. They also provided counselling to individuals and families regarding social and emotional problems, working with the nurses, social worker and RCMP. When the court placed someone on probation and there was no social worker, the community wellness worker would fill in. For the most part, the counselling done was working with the individual, couple or family to help them identify strategies for dealing with minor life skills problems, such as money management and conflict resolution. This position was filled by a community member with no special preparation.

Formal Health Care Outside the Community

The referral centre for Kugaaruk is Yellowknife where there is a regional hospital and basic specialized services, such as ultrasound, operating rooms, intensive care and dialysis. Advanced services—oncology, specialized surgery and advanced diagnostic testing, such as MRI—are located in Edmonton, Alberta, approximately 3,000 kilometres away by air (a two-day trip by scheduled air transport).

Hospitalization

The Health Centre is staffed as an outpatient facility, and anyone requiring hospitalization is therefore transferred to Yellowknife. Patients for elective admissions are sent to Yellowknife on scheduled flights. Individuals with acute illness or injury are admitted to the Health Centre until transportation can be arranged. This requires a

medivac flight and, in good weather, takes between two and eight hours, depending on the availability of aircraft and flight crew. On several occasions, because of weather in either Kugaaruk, or where the plane was, or Yellowknife, it took 24 hours. The result was that the two nurses had to staff round-the-clock care as well as operate clinics. When possible, the nurses would adjust clinic attendance to accommodate their increased workload. At times, such as during bronchiolitis outbreaks, this was impossible, as the same illness of the severely ill child requiring hospitalization was affecting many other children who required treatment and monitoring in the hope of preventing hospitalization.

Health Promotion

The Nunavut government periodically initiates a health promotion campaign, which involves media campaigns and the distribution of materials to the community through the Health Centre. During the research period, these initiatives included material on FAS, influenza, and suicide awareness and prevention. As part of the suicide prevention initiative a task force was formed and the Community Health Representative from Kugaaruk was chosen to participate as a task force member. This task force visited communities and met with families and community members. It made a number of recommendations in its final report.

In summary, Health Care services in Kugaaruk are modeled on a Western biomedical model introduced by Health Canada in the 1960s. The organization and scope of services has changed little since then. Treatment options available to nurses are biomedical, limiting the nurses' ability to offer alternative services. The increased population, aging population and increased acuity have increased the demands to provide acute intervention services, leaving little time for health promotion activities at a local level. Mental health services are inadequate and fail to deal with underlying causes.

CHAPTER 5
THE HEALTH CARE DECISION-MAKING PROCESS

The health care decision-making process is a series of decision points, and at each point, factors influence the decision being made at that time and on that occasion. This chapter will describe the health care decision-making process of the Inuit in Kugaaruk. Initially, I will discuss health care decision-making as it relates to illness management, followed by a decision making related to health promotion and disease prevention activities. Health care decision-making related to illness management was found to be similar to the five-step model of decision-making as described by Brink (1977), including relevant points by Twaddle (1979) and others.

Deciding a Person is Ill

The first step in the process was the decision that a person was ill, which was dependent on the identification of either a behaviour or a symptom that was unusual for that person, and then associating that behaviour with illness. This step was also identified by Brink (1977) and Twaddle (1979), although Twaddle identified it as the second step. Minor illnesses such as colds, fevers, mild gastrointestinal illnesses and minor aches and pains were often described as "not being well" or having "a bit of a cold," but when asked what that meant, they would simply say they were not ill. "Not being well" was treated with over-the-counter drugs and/or an alteration in the activities of daily living such as staying home from work, sleeping and not going out to visit as much. No Inuit home remedies were seen.

Self-care was most often practiced until symptoms did not go away and/or were classified as an illness, at which time people consulted with the nurses. People talked about how before the nurses were in the community they had consulted with the Catholic priests, and prior to the arrival of the priest, they indicated a shaman had been used.

Betty noticed that her son's behaviour was unusual one Sunday "He was okay, he was fine [during church]. After church he went to bed." Betty's decision to take Ben to the Health Centre was based on this behaviour being very unusual for Ben and

the fact that he had been ill several weeks earlier, and she thought they might be related.

Rachael noticed a change in behaviour in her son, John. He complained of stomach ache, was not eating, and was not interested in his usual activities, such as going to the gym or playing with his friends. John had had an "upset stomach" in the past, which went away on its own, and Rachael and her husband associated the stomach ache this time with those other stomach aches. At this point, John's symptoms were not attributed to an illness but as an attempt to get his parents to give him junk food. The next day, he was sent home from school with the stomach ache, and it was then noticed that he vomited when he tried to eat. This caused Rachael and her husband, Jerome, to become unsure of what was wrong. Vomiting from meals was not only an unusual behaviour for John, but was also seen as an immediate and severe symptom. Jerome phoned the Health Centre and John was seen right away and later sent to hospital with a suspected acute abdominal infection.

Harriet's baby's illness started out as a slight fever and nasal congestion, which she and her husband associated with a cold, and they treated it successfully themselves with steam inhalations. Later in the evening, when the baby was sleepy and cranky with the fever, Harriet became worried and took the baby to the Health Centre. She stated that she knew other babies were similarly sick with colds in the community, but she had become concerned that the baby might have meningitis. Harriet stated that she had an older child who had had meningitis and was brain-damaged from it. The child with meningitis had not been very sick at first, but then got ill very quickly and had to go to hospital. With this baby's illness, she started thinking about her older child and worrying, so she brought the baby to the nurses and "asked [the nurse] if it [the illness] was meningitis"; he told her no, it wasn't. After that, she was not as worried about the baby, and could see that the baby was getting better. Harriet had previous experience with meningitis and was afraid that the sleepy crankiness and fever might indicate the onset of meningitis so she consulted with the nurses.

Isaac was an active and successful hunter who developed problems with his balance, which he noticed over a period of days. He was unable to stand upright

without holding on to something, his gait was unsteady, and he felt like he would fall. Isaac and his family attributed this change in behaviour, when it persisted for two days, to an illness. The nurse could not identify a reason for this change in behaviour and consulted with a regional physician, who recommended observation. Over the next two days, Isaac was assessed daily by the nurse, who consulted with the physician. His condition neither improved nor worsened. On the third day, the nurse was convinced further investigation was required and contacted a doctor in Yellowknife, and Isaac went to Yellowknife for assessment. There he was diagnosed as having a brain tumor. This illustrates that when the change of behaviour was dramatic and the individual and family had no frame of reference with which to associate it, they sought help to explain the behaviour.

Symptoms

The nature and severity of symptoms were also factors in health care decision-making. If symptoms were associated with a known health problem that was understood to have serious implications, or if they were totally new and therefore not associated with a known health concern, people were more likely to take action, which might include seeking advice or care. In children, especially infants, respiratory symptoms, diarrhoea and vomiting were generally identified as symptoms that required immediate action. Infant mortality from illnesses with these symptoms, although improved from the past, is higher than the national average and is generally recognized by family members. Every family in the community was able to remember at least one infant in their family who died as the result of either a respiratory or gastrointestinal illness. Most people know the basics about treatment of these illnesses.

Change in Behaviour

Behavioural cues were often part of health care decision-making. When an individual's behaviour altered, one of the considerations was whether it was because of illness. The link between illness and the changed behaviour was not always clear to the people involved and, as a result, the change in behaviour was, at times, initially misinterpreted. Rachael related that at first she and her husband had thought her son John's refusing dinner and not playing was related to his wanting "junk" food. It was

only when the behaviour persisted and he complained of pain and reasons that they linked the behaviour to his being ill. The situation with Isaac was very different. Isaac and his family became concerned when he started to have trouble with his balance and became unsteady on his feet. They sought assessment from the nurses when it did not resolve on its own. They indicated that as it had not resolved, it might be something to be concerned about, and they thought it might be something serious as it affected even his walking.

Deciding on the Severity of Illness

The second step in the decision-making process was deciding on the severity of the illness. This step is consistent with the second step identified by Brink (1977) and the third step identified by Twaddle (1979). In the case of Isaac and his change in balance, initially he waited to see if the problem went away on its own. When it did not resolve, he and his family became more concerned. The illness was perceived as serious because of its persistence and the nature of the behavioural change. This was validated by the nurses when they sent him to hospital by medivac for further investigation. When Isaac was preparing to go out of the community, he made a point of saying goodbye to all his children and grandchildren in case he did not have another opportunity; on his return to the community, he was grateful for more time with his family.

Natasha, like many other three-year-olds in the community, frequently had a runny nose. Her mother, Wendy, attributed this to her having a cold. As long as Wendy did not have a fever or demonstrate other symptoms of illness such as a cough or irritability, Wendy thought the illness did not require treatment. If a fever developed, she was comfortable self-treating with Children's Tylenol. If other symptoms did appear, such as a cough or wheeziness, then it would be considered worse than a cold.

In contrast, when Natasha's six-month-old baby brother, Daniel, developed a runny nose in the spring, when bronchiolitis usually occurred, Wendy had him checked by the nurse. She stated that as an infant, Natasha had had to be hospitalized twice for bronchiolitis at Daniel's age. Symptoms were interpreted based on the

person's age and the mother's previous experience, regardless of the severity of the symptoms. The prevalence and severity of respiratory illnesses in infants in the community resulted in most respiratory illnesses in infants being at least potentially serious and worthy of seeking consultation and treatment. Although the symptoms were the same for both children, Daniel's symptoms were considered more serious because of his age.

Carl's job is strenuous and he occasionally has lower back pain. In the past, he went to the Health Centre and received medication for the back pain. With medication and rest, it usually resolves over a couple of days. He now buys Tylenol Back Pain medication from the Co-op and takes that for the pain, only going to the Health Centre when the pain persists. Self-treatment occurred when symptoms were identified and sufficient knowledge and resources were available without seeking further assistance.

Deciding to Seek Treatment

The third step in the decision-making process was the decision to seek professional treatment. This step is consistent with the third step identified by Brink (1977) and the fourth, fifth and sixth steps identified by Twaddle (1979). In the case of John's stomach ache, as long as it was consistent with previous stomach aches, his mother was comfortable treating it as she had in the past, by letting him rest and eat as he pleased. When John's symptoms changed and became more severe, treatment was sought. While Rachael stated they often sought advice from her father-in-law about health matters, in this case her husband decided to take him to see the nurse, as he seemed very sick.

Frank was involved in a road accident when his foot was caught under the wheel of his All Terrain Vehicle (ATV) one early evening. He was in considerable pain and could not stand. Although the clinic was closed for the day, the bylaw officer obtained a stretcher from the nurses and took him directly to the clinic. He had badly injured his leg, which required surgical repair. Even though the clinic was closed, it was recognized that Frank need to be treated immediately. The nature of Frank's accident, his pain and the malposition of his leg indicated to the bylaw officer and others at the site that he required medical services.

Many young parents stated that they would seek the advice of an elder in their family about whether a change in behaviour indicated an illness. In practice, few ever did so unless the elder was physically present. Amy, a 60-year-old mother and grandmother, would tell her children to go and see the nurse if asked what they should do about a sick child. Other elders, when questioned about advice they would give if asked about common illnesses such as diarrhoea, vomiting, fever, or colds also indicated they would advise going to the nurse.

Sources of Treatment

The third step in the decision-making process identified by Brink (1977) was the decision as to where to seek treatment, or which healer (if more than one was available) was the most appropriate or accessible at the time. Similarly, Twaddle (1979) identified three steps relating to the type of treatment that should be sought, and from whom. For the residents of Kugaaruk, and many other communities in Nunavut, there is only one source of health care: the Community Health Centre which provides Western biomedical health care. Community members self-refer to services provided by the nurse. (Physician services and services outside the community, covered by the Territorial Health Care Plan, are all biomedical in nature and are dependent on referral by nurses or visiting settlement physicians.) Reliance on Western biomedicine goes back to the earliest years of the settlement, when medical treatments were provided by the Catholic Fathers of the mission, and was further developed with the introduction of nursing stations by the Federal government.

Alex said that when his children were small and had the flu (approximately 50 years ago), "our only hope was Father [the priest at the mission]. He tried nursing them and all that, but, you know, what could we do at the time…Today it's not so bad because we have the nurses now in town". All the elders talked about Father providing medical care to them and their children.

Josh and Helen described how one of their children had developed a skin condition that had a slight effect on his appearance. He was sent out by the nurses to Yellowknife to see a specialist, who diagnosed the condition. The medication for the condition, however, had serious side effects because of his age, and so treatment has

been postponed until he is older. The condition was not seen as life-threatening, so this was agreeable to Josh and Helen. In the meantime, Josh and Helen regularly prayed in church for their son to get better. After a couple of years, the skin condition went away on its own, which they attributed to the power of the prayers. The only time I observed prayer taken beyond the family, for illness, was when Isaac was sent out for his altered balance. After it was discovered he had a brain tumour, there was a church service for him at the Catholic Church. While Isaac did not regularly attend church, people described him as a spiritual person. It was evident by what a number of people said about him that he was well liked and respected. The service consisted of people giving testimonials and the priest leading them in prayer.

Nicholas, a young man in his late 20s, was known as being aggressive and subject to delusions. He spent time in jail for violent behaviour and people, including his family, are uncomfortable around him, and some are even afraid. One person commented, that "he would be considered a shaman in the past." Despite the overcrowding in the community, he lives alone. One of his delusions was that while he was in jail, someone had read his journal, in which he had written the idea for the BowFlex (a piece of exercise equipment) and had stolen the idea and was now a millionaire. He wanted to sue this person and be compensated for his idea. Occasionally he would get very agitated, and on one occasion, the RCMP had to help settle him down. Their presence and willingness to listen to him helped him calm down. He regularly talked to the nurses and had telephone sessions with the psychologist and when his behaviour became consistently agitated, he would be sent out to Yellowknife for a few days for face-to-face sessions with his psychologist. Nicholas was on medication, which he did not take regularly. He stated he had been told by a social worker that he had schizophrenia, but he said the nurses told him there was nothing in his chart giving a diagnosis.

When to Seek Treatment

The timing for seeking treatment was not covered in the process described by Brink (1977) or Twaddle (1979), yet was an integral part of the decision-making process in Kugaaruk.

Rebecca, like many other people, was looking forward to the regional hockey tournament that was taking place in the community. She enjoyed the fact that friends were coming from other communities, either to play in or watch the games, and actually had several people from other communities staying in her home. The five days were filled with both the entertainment of watching the hockey games and visiting with people from the other communities. She did admit the late nights at the arena were wearing her out. She took her four-year-old daughter, Pam, with her and, as a result, Pam did not get as much sleep as she usually did. By Friday, Pam was cranky, had a cough, and runny nose. "She's getting sick, but there's no one to watch if I leave her at home, and it's only one more night anyway". On Monday Rebecca booked an appointment for Pam to be seen during sick clinic at the Health Centre. The nurse told her Pam had a bad cold and needed rest and fluids. She was told to give Tylenol for fever.

In my observation it was common for people to ignore minor illnesses when there was something else going on which, at that particular time, had a higher priority. These included community-wide events such as the Christmas celebrations and the hockey tournament, or getting to the store before it closed for the day. Once the event was over, they either waited for the next clinic day to make an appointment or called the nurse and asked to be seen outside of clinic hours, based on how severe they judged the illness to be. As a result, clinics at the Health Centre were exceptionally busy following community events. The nurses indicated that the Health Centre was closed for several days due to statutory holidays, they had to see more people after-hours. This was expected, and attributed to limited regular clinic hours and longer periods of closure due to long weekends.

In some cases, health considerations were secondary to the desire to go out "on the land." Paula, who had a respiratory infection, and her husband decided to go out camping, despite her underlying lung disease and having been advised by the nurse that she had an chest infection and needed to take antibiotics and get lots of rest. The attraction of getting out "on the land" while the weather was good took precedence over the advice she had been given. To her, being out on the land was restful, even if it

was physically more demanding than staying at home. When Paula and her husband returned to the community a few days later, her infection was worse and she needed to be sent out to hospital.

Deciding to Follow Treatment

The fourth step in the decision-making process involved the decision to remain under the care of the health care provider, through resolution of the problem or death. This step is similar to the findings of Brink (1977) and Twaddle (1979). Many of the infants with respiratory symptoms were treated with inhalation therapies, and parents were expected to participate in their child's care. This often involved outpatient inhalation therapy, every four hours around the clock, and at times, this treatment was increased to every two hours. This protocol required a great deal of time and commitment from the parents and other family members. While manageable in the short term for most families, there was a point at which it would become a strain particularly if the treatments did not produce any marked improvement. Trevor's mother and father expressed frustration because his mother had been administering inhalation treatments every two to four hours for two days, and the nurses were not sending him out to the hospital despite several other infants being sent out for bronchiolitis and RSV. To Trevor's parents, those children did not seem any sicker than Trevor. On her visit to the Health Centre, Trevor's mother snapped at the nurses and asked that he be sent out. The assurances that the treatments were working and that he would not be admitted to hospital if sent out did not completely alleviate her concerns, nor did reassurances from her sister that her own children, when they had had bronchiolitis, had required similar treatments and had eventually improved. She continued treatments, as she did not see that she had any other option.

The first step was that there had to be an acceptance of and agreement with the diagnosis in order for people to be willing to follow treatment. When this did not occur, one of a number of things happened. The ill person, or his or her family, would try to get a second opinion from the other nurse. There were, however, several barriers to this option. People could not request which nurse they wanted to see, and often saw the same nurse on return visits to the Health Centre. If it was after-hours, they would

have to see the nurse on call, who remained on call for up to 24 hours. There were usually only two nurses at the Health Centre, and they often discussed patients, increasing the possibility of one influencing the other. With no other treatment sources in the community, the choice not to follow treatment meant not being treated at all.

The autonomy of children to make their own decisions extended into the health care decision-making process. Although parents would offer them their medication, it was often up to them whether they took it or not. Sandy was the 23-year-old mother of eight-month-old Tammy, who had a high fever. The nurse had instructed Sandy to give Tammy a tepid bath. Sandy did put Tammy in the bath, but only for a few minutes as Tammy did not like it and kept holding out her arms to be taken out. Even though Sandy understood the bath was meant to help lower Tammy's fever, if Tammy did not want to stay in the bath, then Sandy would not make her.

Children were considered not just children but also, in some way, the person for whom they had been named. Sylvia talked about how her eight-year-old had been named after her dead mother and was, therefore, not only her daughter but also her mother, and would often refer to her as "mom." This autonomy of children is also apparent in children's behaviour. At public events, such as church services, children wandered around freely, playing in the aisles, running about and visiting with people. It was only when they attempted to go in a restricted area, such as the altar, that they were prevented from doing so by being gently redirected by adults or older children.

Deciding a Person is Well

The last phase of the decision-making process was the decision that the individual was well and no longer needs treatment. While Brink (1977) identified this as the final step, Twaddle (1979) ended the process with the decision to follow treatment.

Tammy had two children, Peter, age eight months, and Jane, age six years. When Jane was both a baby and a toddler, she was given antibiotics on numerous occasions for ear infections. Tammy said she would give the medication until her fever stopped and she did not see any discharge from her ear. Jane would be well for a short while then her ear would start draining again and she would need more antibiotics. When

Peter had an ear infection, she continued giving him the antibiotics until the course of the medication was finished, as the nurses had instructed, even though the fever had stopped and there was no discharge from his ears. She noted that by finishing the medication she prevented the infection from coming back, and in future she planned to make sure her children finished the medications.

The predominant indicator of return to wellness was the resolution of symptoms or abnormal behaviour. This decision is made by the client and their social network and may or may not be confirmed by the nurse. In cases where symptoms persist even after biomedical "cure" has occurred the person is still considered ill until the symptom is resolved.

Some children who have had bronchiolitis have a residual wheeze for a period of time. This wheeze is benign and, in paediatrics, the term "Happy Wheezer" has been used to identify this phenomenon (Cochran, 1998). Dennis and Trudy, parents of a 15-month-old, Nathan, who had had bronchiolitis a month earlier, continued to be concerned about Nathan's wheeziness although he was a happy and active child. Although the nurses reassured them on a regular basis and explained why he was wheezing, they continued to take him to the Health Centre for the wheeze.

On the occasion when symptoms reoccurred, it was most often linked to a new illness, rather than a resurgence of the previous illness. This perception seemed to be gradually changing as people learned more about illnesses.

Chronic disease was viewed somewhat differently. Chronic disease was not considered an illness state, but rather a condition they have which does not define their wellness. Norman, a 67-year-old man, considered himself well despite chronic respiratory disease and pain in his joints. When he had exacerbations of these conditions, he did not consider himself ill, as long as the changes were within his defined of range of symptoms he associated with his chronic condition. He considered the purpose of treatments to be to return him to his state of wellness. It was only when he had symptoms or behaviour changes in addition to his chronic condition that he considered himself ill. This occurred when Norman developed a fever and his sputum became green and very thick, both of which were outside the parameters he considered

normal for his respiratory disease and that he associated with an infection rather than the chronic condition.

Health Promotion and Disease Prevention

Health promotion and disease prevention activities were not part of the illness model described by Brink (1977), yet Twaddle (1979) believed that the first step in health care decision-making involved the decision that the person was well and described what the person did to remain well. Health promotion activities can include lifestyle choices that have an effect on health and well-being. Disease prevention refers to activities to mitigate threats to health, and thereby avoid disease. Although health promotion and disease prevention decision-making do not have the same decision points as decisions about illness management, there is a decision-making process to engage in health promotion and disease prevention activities.

Deciding a Person is Well

Participants equated wellness to well-being and to engaging in traditional activities. That people felt revitalized after spending time out on the land reinforced this view. They described having more energy, and a more positive outlook on their lives. My own experience was that after being confined to the Hamlet for the long winter months, getting out of town was invigorating. Being out on the vast expanse of tundra was humbling, while at the same time inspiring. One does feel a relationship to nature.

Well-being was often related to having participated in activities occurring outside the boundaries of the community. This varied from just going outside the community to the river to fish, to going to "camp for the weekend". Many of the families in the community have permanent camps within a 30-kilometre radius of the community. In the summer months, they spend as much time as possible at their camps hunting and fishing. Many have facilities that can also be used during the winter months. Caribou and char are the main sources of protein for the Inuit and are identified as "healthy food."

Wellness was attributed to living well and being productive. While drug and alcohol use was becoming problematic in the community it was not generally

approved of by most community members. Elders expressed concern about many of the things they saw young people doing, such as drinking, doing drugs and gambling, which affected the overall health of individuals, families and the community. These activities were seen as the cause of many of the social problems in the community, such as family violence and problems with youth. At a community meeting that resulted from several children being found sniffing gas, community members expressed concern and noted that the children were unsupervised by parents who were busy gambling. The general feeling was that if the parents were more involved in traditional activities, then they would be less likely to or to use drugs and/or alcohol.

Gambling was broken down into two categories: acceptable and problem gambling. Radio bingos, held several times a month and used for fund-raising, were considered acceptable and were extremely popular with everyone in the community. The afternoon before the bingo, cards would go on sale at the community hall, and most people bought between 5 and 10 cards. That evening, the bingo was conducted with numbers being called over the local radio station. Players would line their cards up on their kitchen tables with their phones beside them and if they won, would phone the radio station. Six games were played each evening. Unacceptable gambling was described as gambling that occurred in private homes and started late at night and sometimes went on until morning, and people would come and go throughout the night. It involved poker. Some people played almost nightly, while others played only occasionally. One informant said that she had relatives who would gamble away their money and then come and ask to borrow from her. Sometimes people would use food in lieu of money to gamble.

Kugaaruk has a bylaw prohibiting alcohol, but drinking remains a problem, as the RCMP can only enforce the bylaw if they are told a person has alcohol or if they are called to the home where drinking is taking place. When they do become aware of alcohol, they will confiscate it, and the individual is fined $50.00. Most of the crime in Kugaaruk was alcohol-related. Of the eleven cases brought before the territorial court during 2003, seven involved alcohol and at least two were related to gambling.

One gentleman, when recently convicted and sentenced for a sexual assault that had occurred 20 years previously, related that the resolution of the case had led him to write a letter to his victim, and that having to face up to his action had lifted a burden he had been carrying around with him for 20 years. This was consistent with the traditional belief that keeping a secret can cause illness (keep you unwell).

Deciding to Participate in a Health Promotion Activity

During my time in the community the prenatal nutrition program run by the community focused on teaching about healthy pregnancies and healthy eating using country foods. It also provided the prenatal women the opportunity to meet weekly to prepare a meal and share information and experiences related to their pregnancy and having a healthy baby. The women learned how to use country foods as an alternative to buying prepared foods at the store. The six to eight women who attended did so for a number of reasons. Some were interested in trying new foods and learning more about cooking with country foods. Others came for the food, which was always prepared in a large enough quantity that some could be taken home for other family members. With many being on social assistance, this was a welcome supplement to their resources. This activity promoted health by encouraging healthy eating and by teaching young mothers how to provide healthy meals for their families. Prenatal health teaching was a component of the program and for several months, weekly information sessions were held, which included information on foetal development, healthy living and nutrition information. The worker involved had received some training as part of the program start-up. In the spring she moved to another community and the replacement worker did not receive the training and was not comfortable holding the classes, so they were discontinued.

The Hamlet organized a picnic out on the land for the elders, some of whom, because of age and/or health problems, did not have the opportunity to get out on the land. The Hamlet and Health Centre provided vehicles to transport them to a picnic spot and volunteers made soup, tea and bannock for them while they visited and shared stories. The elders, especially those no longer able to get out on their own,

enjoyed the day and were uplifted by an activity that promoted their sense of wellbeing.

Deciding on the Presence of a Threat

The decision that something was a threat to health or wellness could be made on an individual, family or community level. While a threat might be identified by the community, such as the concern about alcohol and gambling, the individual made the ultimate decision on whether to act on that threat.

Young people are especially susceptible to STDs in Kugaaruk. Based on the number of condoms taken from the dispensers (boxes in washrooms and entryway) at the Health Centre, condoms apparently are used. People admitted they often had unprotected sex if the sex was associated with the use of drugs and/or alcohol. Young people know that the STDs they or their friends have had, such as Chlamydia, are treatable. There is a sense that these are the only STDs for which they are at risk and because they are treatable they are not viewed as a serious threat. In the summer, southern workers in the community, working on construction, often have sexual relations with local women, who then have sex in the community. The potential for HIV from such relationships is not fully understood or appreciated.

Suicide is identified as a major threat in the Inuit population. Although Kugaaruk has not had a suicide in several years, there was one attempted during the period of this study. A young woman had taken an overdose of over-the-counter drugs while intoxicated. She was treated for a few hours with medication at the Health Centre, and then she left even though the nurse had wanted her to stay and complete a treatment for the overdose. No reason other than intoxication was ever expressed. Most people had a family member or friend who had committed or attempted suicide. Tony, whose son committed suicide over 10 years ago, expressed his concern and bewilderment. He did not understand why someone would commit suicide and was at a loss as to how to prevent it. Since loss due to suicde affects so many people, it is perceived as a threat not just by individuals, but also by the community and the government.

Communicable diseases, such as tuberculosis, meningitis and measles, have occurred in the past. Like other communities in Nunavut, people were aware of the

potential for these diseases and this was one of the reasons they were supportive of childhood immunization. Several individuals stated they had had tuberculosis in the mid-1950s, and one woman had had polio as a child. Meningitis occurred on a regular basis until the 1990s, when immunization for *Haemophilus b* was initiated, and several women said they had lost a child to this infection. No one could recall a recent case of tuberculosis or measles in Kugaaruk itself, but cases in neighbouring communities were known to have occurred in recent years. Since people regularly travel between these communities, it is acknowledged that a threat does exist.

Diabetes and heart disease are seen as of little or no threat. While some people knew of these health risks, the actual incidence is very low, and no one had the disease or knew of anyone who was affected by these disorders.

Deciding there is a threat of illness could be based on a number of factors. In the case of obtaining immunizations for influenza and other communicable diseases, the threat was based on past experience of the individual, family or the community. The extensive media coverage of the SARS outbreak in Toronto and later deaths of children in the US, and then in a nearby community, increased the perception of threat from influenza.

The number of vehicles in Kugaaruk has increased over the years, and they are beginning to be viewed as a threat. All Terrain Vehicles (ATVs) and snowmobiles are the most common form of transportation for families in the community, and are most often treated as a family vehicle. These vehicles are driven on the roads in the Hamlet, but are also used to travel out on "the land". It is not unusual to see an ATV or snowmobile, meant to carry at most two people, being driven with four or five passengers in addition to a driver. Moreover, these are often driven very fast. At several Hamlet meetings, councillors raised concerns about the safe operation of these vehicles, both with regard to the number of passengers and the speeds driven. Most could give an account of almost being hit while walking, or describe near-accidents with other vehicles, such as the water truck. Concern was also expressed about the age of some of the drivers. There were bylaws about operation within the Hamlet, but these were rarely enforced. While accidents and injuries were usually minor (bruises

and scrapes), several were serious. In one snowmobile accident just outside of town, a woman's scalp was pulled back from her forehead to beyond her ears and required extensive suturing by the nurse on call. In another case, the driver of an ATV suffered a fracture of both the fibula and tibia and a dislocation of her ankle, requiring orthopaedic surgery.

Evaluation of Threats

Once a threat was identified, the severity of the threat was determined and the perceived severity of the threat was the major factor in determining if any action would result. When the threat is viewed as real, important and existing in the present time, action took place. In my observation motor vehicle accidents were viewed as a serious and immediate threat. Recommendations made at Hamlet council were: posting speed limits; bylaws regulating a minimum age for drivers; number of riders on a vehicle; and the use of helmets. There was, however, resistance to these bylaws, as most families were large and had only one vehicle, so continued to have multiple passengers.

The evaluation of threat was also demonstrated in the high rates of immunization in response to the threat of communicable disease. During the study, the threat of influenza was considered severe because of the community's history with influenza and perhaps because of the media coverage of SARS during the summer. The threat became current when several children died from the current strain of influenza, first in cases in the United States and southern Canada, and then in a nearby community. As a result, most people in Kugaaruk attended influenza clinics and, according to nursing staff, at least 85% of the population had received influenza immunization.

Other threats were considered serious but not as urgent, such as suicide. The Inuit in Kugaaruk were aware of the high incidence of suicide among the Inuit in Nunavut and many people had lost immediate or extended family members to suicide in the past. This threat, however, was less immediate than others, because there had been no recent suicides. There was a sense of powerlessness associated with suicide. Ken, whose son had committed suicide 13 years ago, stated he had heard the suicide rate was much higher in Nunavut than in the south, and that it happened to good

parents and often in broken homes, but he didn't know why it happened or what could be done about it. Nevertheless, the threat was seen as real and the community attempted to deal with it by identifying individuals (whose names could be posted) to be contacted by anyone contemplating suicide to talk. This list included elders, the wellness worker, the Community Health Representative (CHR), the RCMP (police) the nurses and the priest. The community sent participants to a Territorial suicide conference and as a result one participant joined a Territorial Task Force on Suicide Prevention and Community Healing. This task force has developed a report with recommendations for community members and policy-makers.

Other risk factors, while acknowledged, were seen as less of a priority. Smoking was known to cause cancer, but sometime in the future, and was not identified as a great threat. There were more immediate threats that assumed priority. The threat of second hand smoke was another matter as it was viewed as a present threat to the health of children. This has resulted in the adoption of smoke-free community gatherings and public spaces. When asked about smoking, people said they no longer smoked in their homes, as it caused ear infections and worsened respiratory problems in their children. When walking around the community, even on the coldest days I saw people standing on the steps outside their houses, smoking.

Aspects of health that were deemed to be of low or no threat were not attended to, other than as a point of interest. Conditions with which individuals or the community had no past experience (such as diabetes) were, for the most part viewed as not something to worry about. Moreover, because diabetes was not a current problem for anyone or their families, it was not viewed as a threat. Research has shown links between aboriginal genetics, change in diet and activity levels, and the development, over time, of diabetes in Canadian aboriginal populations (Young, Reading, Elias & O'Neil, 2000). The association of diet and exercise with diabetes, and the implications for developing diabetes, were not well understood by the community. In addition, there was little understanding of the nutritional value, or in some cases the lack of nutritional value, of store-bought foods. At nutrition sessions held by the regional nutritionists, women were surprised when they were shown the

amount of sugar in commonly used, store-bought foods. No distinction was made by the Inuit between fruit juices and fruit-flavoured sugar drinks, or between sugar-frosted cereals and non-frosted with regard to nutrition. Ken found it odd that the stores would sell food that was not good for you, such as pop and chips. Since he believed that all Inuit food was good for you, he wondered why store-bought food was different. (He applied this same thought process to drugs and alcohol, wondering why they were made if they were so harmful.) Some people expressed a belief that because diabetes had not happened in the past and was not currently a problem, it was not likely to happen in the future.

Some concerns such as drugs, alcohol, gambling and associated behaviours (e.g. family violence) were identified as a serious and immediate threat. These problems were talked about at community meetings and identified by elders and community leaders as a serious and existing threat. Elders expressed the opinion that there was a relationship between a decrease in young people engaging in traditional activities, such as hunting and spending time on the land, and the increase in these problems. Jane felt that many people were hurting from past events, such as abuse, or present situations, such as overcrowding, which led to these unhealthy activities.

The decision that a risk was a threat was also influenced by knowledge of the human body; knowledge of the risk factor (such as the medical condition); and the implications of ignoring the risk. While most people understood gross anatomy from their familiarity of the animals they hunted and processed for food, this did not include an understanding of the endocrine system or diabetes or the implications of STDs.

Deciding to Access Services or Change Behaviour

When an individual or group decides that a risk is great enough to seek assistance, the Health Centre remains the main access to services, and while health promotion and disease prevention programs and services are somewhat limited by the resources available to the nurses and community health representative, this remains the main resource. Regular immunization and focused health clinics such as Well Woman, were routine and well attended.

The screening component of the Well Woman Clinic, such as PAP smears and breast examinations, were accessed based on the advice of the nurses rather than on the perceived risk of this event, although the risks are present. The incidence of cervical cancer among the Canadian Inuit is 15% compared to 9.7% for the rest of Canada (Franco, Duarte-Franco, & Ferenczy, 2001) while the incidence of breast cancer is not significantly less than the general Canadian population (Nunavut, 2004)). Women said that while they knew the reason for the screening, they attended the Well Woman Clinic and had the screening because the nurses advised them to, rather than because they perceived a risk of getting cancer. No one in the community knew of anyone who had had this type of cancer. The screening programs for breast and cervical cancer are part of the national screening recommendations and have been adopted by the Nunavut Department of Health.

There is no similar established screening program for colorectal cancer, despite the incidence of this type of cancer being significantly higher in the Inuit (80.5/100,000) than in other Canadians (18.4/100,000) (Nunavut Department of Health and Social Services, 2004). The approach adopted by the Department for colorectal cancer is to focus on the preventative aspects of a good diet, rather then screening (Nunavut Department of Health and Social Services, 2004)

There are few services available for social and mental health concerns. There is the Nunavut Kamatasiaquit HELP line, based in Iqaluit, to provide personal and crisis counselling between 1900hr and midnight every day (Kamatsiaquit, n.d.). For the most part, however, people preferred to access services through the Health Centre or the community wellness worker employed by ~~at~~ the Hamlet. People expressed the need for more services locally. At the Kitikmeot Inuit Association Annual General Meeting, which was held in Kugaaruk in 2003, delegates from Kugaaruk and other communities expressed a need for more services at the community level to deal with social and mental health problems such as a safe house, addictions programs and mental health workers. Although invited, no government representative was present to address these concerns, and this fact was brought up numerous times by meeting organizers.

There were some local responses to some of these problems. In response to the threat of suicide, the Hamlet sent two delegates to a weeklong national conference of the Canadian Association for Suicide Prevention (CASP) in Iqaluit. As a result of this conference, a territorial task force was established that developed 34 recommendations for suicide prevention and community healing (Nunavut Department of Health and Social Services, 2003a). The eight central themes of the recommendations were: fostering communication of feelings and problems; fostering self-esteem and pride in being Inuit; valuing, supporting and caring for one another; evaluating terminology around suicide; supporting young people; retrieving and maintaining skills for healthy lifestyles, using Inuit knowledge and values; supporting existing workers at the community level; developing more services (formal and informal) at the community level; and taking ownership of the problem. Following the conference, community leaders started a community-based crisis team of professionals, such as the nurse and RCMP, volunteers, including elders, and other community members. This involved developing a list of people who volunteered to be on a list that would be made public so people could call them if they were in crisis. This was not meant to replace the territorial HELP line but as an additional community resource.

Alternative sources of health promotion were limited to what was available through the media and Internet, such as vitamins and exercise equipment. Only a few people accessed products in this way. No alternative Western biomedical health promotion services--such as massage therapy, yoga and chiropractic--existed and even if they did, their cost would limit use.

Even when people tried to use the Health Centre for health promotion programs and services, there were barriers. The nurses provided individual counselling and assistance; however, the clinic hours and their workload made group initiatives difficult. Many group activities lacked leaders with the knowledge and/or skills to provide health promotion programs. A food mail program, which subsidized the costs of bringing fresh produce into the community, had a health promotion component, but minimal training was provided to assist the worker in developing the skills to fulfill this role. Similarly, the community wellness worker had no training for her role. Both

these programs were funded by the Federal government and were developed in isolation from the Health Centre and the Nunavut Department of Health and Social Services.

Some health promotion products, while available, were often not utilized because the window of opportunity was lost. A person who wanted to stop smoking could obtain nicotine gum through the Health Centre. This was treated like a prescription drug and would take one to two weeks to arrive in the community. On many occasions enough time had transpired that people did not pick up their prescriptions. For example by the time the nicotine gum arrived the person had lost their resolve and did not bother trying the gum.

Regular public health clinics, such as Well Child and Well Woman, were well attended, and women were aware of the risk of cancer; however, they did not see themselves as being at high risk, even though they attended the clinics and participated in screening. The high attendance may be the result of the clinics having been operational in the community for long enough that they have become a normal part of people's health routines. Well Woman and Well Child clinics have been established in their present form for at least 20 years (personal knowledge). Women saw taking their children and themselves to these clinics as a normal event. This might explain, in part, why Well Man clinics are not as well attended. Well Man clinics have never been sustained long enough to become a routine event, and men were not used to going to the clinic unless they were sick.

Social Context of Decision-making

Decision-making takes place within a social context. Family and friends are involved throughout the process. They provide advice, validate decisions, and provide support and assistance. Life experiences, especially those related to health and illness, are used within the decision-making process and are integral to the decision-making process.

Influence of Others

The people of Kugaaruk are close to one another. They are often related at some level by blood or marriage, and have known each other their entire lives. This

familiarity results in people being open to influence, even in situations that would normally be considered social. The influence of others does not occur at any single point in the process, but at all points, and may be solicited or unsolicited.

Shelly, a post-partum mother, was at a prenatal cooking class. At numerous times during the evening, Shelly's four-month-old infant spat up a small amount of milk. On each occasion, Jenny, another pregnant woman, stated that the baby must be sick. Initially, Shelly responded confidently that the baby was fine. Over the evening, Shelly's response that the baby was fine became less confident, and by the end of the evening, she was seriously considering that the baby might be sick, and if it continued to spit up, she would take it to the Health Centre to see the nurse in the morning. While Shelly did not take the baby to the clinic the next day, Jenny's comments about her baby's health clearly disturbed her, despite the fact that this woman was not yet a mother and therefore less experienced than Shelly.

A belief that prenatal vitamins would result in a baby being "too big" was common among the women of Kugaaruk. The basis of this belief was unknown to younger women, as well as to some elders who were interviewed. One elderly woman said that having "too big" a baby could make delivery difficult. Many of the prenatal women admitted they did not take their vitamins for this reason. Others said they were not taking their vitamins during this pregnancy, even though they recounted that they had taken their vitamins during previous pregnancies and their babies had been of normal weight.

The role of family and friends in influencing the health care decision-making process is consistent with that described by Maly, Umezawa, Ratliff, and Leake (2006), in which individuals share decision-making with others. The relationship between the individual making the decision and the friend(s) and/or family member(s) involved determines the degree of influence the friends and family have. The closer and more trusted the relationship, the stronger the influence. The final decision about illness and health, however, rests with the individual. Jenny, a 66-year-old woman with advanced respiratory disease, was weak and not breathing well because of her condition. She was on home oxygen and was told by the nurse and physician that she

was receiving the maximum amounts of all her medications. Yet she continued to smoke. The nurses and physician advised her that the only way she would get any better at this point was to stop smoking, which she decided not to do. Her family and friends accepted this decision.

Past Experiences with an Illness

Michael, an 18-month-old, had had bronchiolitis when he was a year old. When his mother noticed one night that he was wheezy, she thought he might have it again. She did chest physiotherapy with him and in the morning, she went to the Health Centre to have him assessed by the nurses to see if he needed inhalations.

An individual's past experience with an illness or health issue impacted ~~on~~ his or her decision-making in several ways. Individuals who had previously dealt with a health problem or concern were more likely to anticipate what was wrong and to have expectations about what treatment should include. They were more likely to initiate a treatment that worked in the past prior to seeking help for minor illnesses. Individuals who had never had an illness experience similar to what they were experiencing expressed some anxiety over the illness and would want to consult with the nurses about their symptoms.

The main distinction between the past experience of the individual or family and the past experience of an illness by the community was the level of influence. While any past experience of illness by the community was influential, the effect of a past experience of an illness within the immediate family was more pronounced.

Just before Easter, there was a gastro-intestinal illness in the community. Everyone was aware that many people were sick for a few days, then quickly recovered. For the most part people saw the illness as a minor one and were not concerned. Jeanie had an 8-month-old nephew who had required daily weight monitoring and an electrolyte oral supplement, so when her 10-month-old daughter got sick she went to see the nurse to see if her daughter needed a supplement even though her friend's babies had been sick and not needed a supplement.

Most of the residents of Kugaaruk have lived their entire lives in the community, and everyone in the community was familiar with severe respiratory illnesses in

infants because of the prevalence and severity of bronchiolitis and Respiratory Syncytial Virus (RSV). One mother talked about how her son, now a healthy seven-year old, had had to be medivaced to hospital 14 times in his first two years for bronchiolitis, and that he knew the nurses in Yellowknife so well he treated them like family members. Bronchiolitis was seasonal historically, occurring from late spring into early summer. During May of my time in the community, three-quarters of the infants under two were sick enough from this illness to require at least one admission to hospital. Approximately half the bronchiolitis cases were associated with RSV, a severe and, at times, life-threatening infection.

There is considerable concern globally today about the threat of a pandemic flu outbreak similar to the pandemic caused by the Spanish Flu in 1918. While the Inuit were spared that pandemic because of their isolation from the rest of the world, they have had their own epidemics, and Kugaaruk has been no exception. One of these was witnessed by Balikci (personal communication, June 10, 2003), an anthropologist in the community at the time. In the spring of 1960, Kugaaruk was a Roman Catholic mission consisting of a collection of stone buildings, the church, the parsonage and storehouses. Approximately 150 Inuit were living in igloos, either at the mission, or in the surrounding area. That spring, an X-ray team came to the community to check for TB. Days after they left, there was an outbreak of influenza. Within days, everyone at the mission was sick, including Father Henry, who normally cared for the sick. No one was well enough to hunt or even go for water (this required bringing ice in from a frozen bay and melting it). After about five days, people seemed to be getting better, and then suddenly some had relapses and died quickly. Help was requested from the DEW (Distant Early Warning) Line station nearby, but there was little they could do. At least 15 people died at the mission in a matter of days, and many more died in the surrounding camps. Everyone lost at least one family member, and some families were decimated.

As a result, the prospect of a flu epidemic was very real to people. This was illustrated a number of times. In April, a four-day regional hockey tournament was held in the community, with participants and fans coming from the other communities

in the region. The population doubled, and activities went well into the night. In the following weeks, there was a mild flu-like illness in the community: people had fevers, generalized malaise, nausea, and vomiting. Enough children and teachers were sick for the school to be closed for several days prior to the Easter weekend. Radio announcements on the community radio were used to give advice on how to manage symptoms and prevent spread. Community Easter activities, except for church, were cancelled. This was significant, as Easter weekend was the annual spring celebration, and usually included several community dances and Ski-Doo races, activities popular with community members.

The community memory of the flu epidemic of 1960 played a part in the success of the annual influenza immunization program in the fall. Approximately 80% of the community had received a vaccination by the time I left the community in late December, and the nurses were waiting for more vaccine to meet requests. A number of people made reference to a relative who had died during the 1960 flu epidemic when talking about getting a family member immunized. Other factors related to the concern about getting immunized were the media coverage of the seriousness of the influenza outbreak in the south, and the death of a child from influenza in another community in the region.

Health care decision-making is a complex and interactive process involving not only the person who is sick but his or her family, friends and to varying degrees the community. Decisions are made within a social historical context. The process of decision-making about health promotion and disease prevention differs from the process related to illness yet both processes are influenced by external factors.

CHAPTER 6
OTHER INFLUENCING FACTORS

To fully understand health care decision-making, there has to be consideration of the many factors that influence the decisions people make about their health and their health care. These influencing factors are not mutually exclusive and can affect multiple decision points in any given health care event.

Environment

The role of the environment in health care decision-making is multifaceted. It consists of the geographic distance of residents to other communities and resources, and the nature of the environment itself.

Distance

While most basic health services are available within the community, many services require appointments in either Yellowknife, Northwest Territories, or Edmonton, Alberta. Decisions to access services that are not provided locally are influenced by distance to the service, the ability to travel to the place where the service is available, and access to services. Some services, such as specialists, physiotherapy and diagnostic tests, require referrals and/or significant advanced bookings. Even when people are in another larger centre with additional biomedical or alternative services, they may not be able to access these services on their own or in the time frame available to them. Currently mammograms are not regularly done as part of the breast cancer screening in Nunavut, as the service is not available in the territory. Women are sent out to a referral centre for investigation but not for routine screening. Instead, women are encouraged to have mammograms done while they are out at a centre for other reasons (Nunavut Department of Health and Social Services, 2004). This does not usually happen for several reasons. Most women over 50 seldom travel to centres large enough to have mammography, and those who do travel often do not know far enough ahead to allow for making an appointment. Services like physiotherapy or massage therapy require serial treatments over a period of time and are therefore not maintainable.

The geographic environment isolates the community, and the only means of transportation to referring centres is by air, and is expensive. Biomedical health travel is part of the formal health care system. Choices outside the formalized health care system are limited to what exists locally and what is available at the local Co-op.

When John had to be sent out for abdominal surgery, one of his parents had to go with him. While waiting for the plane, they changed their minds about this several times. The trip would disrupt their lives, no matter who went. If Rachael went, Jerome would have to take on responsibility for their 18-month-old infant, and Rachael would miss time from a course she was taking at Nunavut in the community. If Jerome went, he would have to take time off work. In the end, they decided Jerome would go, as it would be more difficult for him to care for their infant and easier for him to take time off work than for Rachael to miss school. Rachel also felt he would be better at dealing with John and his surgery.

Tess was going to Yellowknife for a tubal ligation and would need to be out of the community for at least five days. Her husband worked seasonally doing construction and was currently working 10 hours a day, Monday through Friday. In order to go out for the surgery she needed to find someone to take care of her three children, ages six months, three and seven years. Her mother was elderly, had severe arthritis, and was not physically able to care for Tess's children. Her sister agreed to take on this responsibility, but Tess was uneasy because her sister sometimes used drugs and gambled. When she participated in these activities, she often neglected her own children, and Tess was concerned that her children would not be cared for. She stated that she could think of no one with whom she would be totally comfortable leaving her children for even a few days. Her sister did agree not to drink, do drugs or gamble while taking care of Tess's children, and managed to keep this promise.

Pregnant women going out for confinement face similar concerns which are magnified as they are sent out to Yellowknife four weeks before their due dates.

The need to travel out of the community for some treatments and diagnostics requires planning and the use of resources to provide for the care of the family members remaining in the community. In addition, the individual, and in the case of

children, the escort, was faced with having to deal with the medical system in an unfamiliar environment, and alone. For some families, it also meant taking time off work or school. These trips did, however, offer the opportunity to shop in a wider range of stores and at lower prices than were available in Kugaaruk.

Nature of the Environment

The Inuit cherish their connection to the land and take every opportunity to travel out to fish, hunt or camp. These activities are themselves influenced by the physical environment, as weather conditions will determine when such activities are possible. While there are roads within the Hamlet of Kugaaruk, only one road extends outside the community, going first to the airport and water plant, and then on to the old DEW (Distance Early Warning) Line site. Going anywhere else in the area requires traveling across tundra or the ocean.

There is a distinct seasonal influence on activities of daily living. During the months of June and July, it does not get dark, and for part of that time, the sun does not set. In the spring and summer months, if the weather is good and travel is feasible, many people spend as much time as possible out of the community, either on day trips or at family camps. ATVs and boats are the main means of transportation. People take advantage of the daylight, warm weather and open water to catch and dry fish. In the dead of winter, the sun does not rise and it is never truly daylight. People spend less time out on the land and are for the most part limited to hunting trips for caribou in the fall and spring ice fishing.

People who have no reason to plan their activities around a clock function on a different timeframe than those who do. In the summer, they may stay up all night visiting, fishing or hunting. The clinics at the Health Centre are based on the clock and are sometimes in conflict with the reality of how people live. The result is that people may want to deal with their health concerns at times not consistent with clinic operations.

Today Inuit live in small, government-built, single-family homes, consisting of one to three bedrooms. These homes are heated electrically and have water and sewage tanks. The construction of these homes is expensive, as materials are brought

from the south by ship in the summer. Supplies arrive late one summer for construction the following summer. Home-building has not kept pace with the population growth and has resulted in a housing crisis in the north (Berger, 2006), and Kugaaruk is no exception. There were at least 20 families on a waiting list for housing. Families who are waiting have to live with relatives or friends.

The Hamlet renovated the elders' centre into a short-term shelter to provide respite for the worst cases until more housing is available. A family living in extreme overcrowding could apply to the Hamlet to have some members stay in the shelter for up to three months, at which time they would either have to return to the home they had come from, or find another place to live so another family could have the opportunity for respite. The first family approved to use the shelter had 17 people living in a three-bedroom house. In the summer months, the ability of people to go to cabins or live in canvas tents also provides some respite.

Media

The Inuit in Kugaaruk are strongly influenced by the media, especially the young. While radio is limited to Canadian Broadcasting Corporation (CBC) Radio One North (regional), television was brought in by satellite and includes all Canadian networks, most American networks, and specialty networks, such as The Learning Channel (TLC), Bravo, the Aboriginal Peoples Television Network (APTN), and other specialty stations. Dial-up Internet is available in the community and high-speed was available at the school, RCMP, Nunavut Arctic College and the Health Centre, with public access through the school. Weekly newspapers come from both Iqaluit, Nunavut, and Yellowknife, Northwest Territories. As a result, people were aware of what was happening, regionally, nationally and globally, with respect to health. When the SARS outbreak occurred in Toronto, Ontario, people were up-to-date on events, and there was consideration given to whether there was a threat to the community once workers from the south started to enter the community to work on construction.

Although not common, in my experience some people did use the Internet to find information on health-related matters. Many people expressed interest in and watched health-related programming; a program that showed actual surgery on TLC was very

popular, as was the channel's programming on the supernatural. APTN provided a nightly news program highlighting Nunavut issues, and often included health issues.

Media coverage on the outbreak of influenza, both nationally and locally, did influence people's health behaviour regarding influenza. Nunavut Health and Social Services provides flu vaccines to all individuals living in the Territory. In Kugaaruk, posters and local radio announcements are used to inform people when vaccines become available, and high-risk individuals are called by Health Centre staff to remind them to have the vaccine. In accordance with Health Canada, high-risk individuals are those who have a high risk of complications from the flu and those individuals who are providing essential services. While many had already been immunized, attendance at immunization clinics increased after the news of a death of a child in a nearby Health Centre, and other deaths in the United States. Some who attended these clinics indicated that while they had been meaning to come in for the vaccine prior to the news, they had been putting it off, and the death influenced them to stop putting it off. Others had felt they were at low risk and had not considered vaccination until after the child's death. At one clinic, a family of five came in. The mother and six-month-old infant had been immunized earlier, as they were both in the high-risk category, but after the news story on the infant's death, they had decided to have the remaining family members immunized.

Resources

Having the resources necessary to initiate and continue treatment is often a factor in health care decision-making. While financial resources are a major consideration, personal resources are also considerations.

Financial

While a limited number of over-the-counter medications are available at the Co-op store, they are expensive: in most cases, at least double the cost in southern stores. The Health Centre carries only a limited number of over-the-counter products, such as acetaminophen. People are encouraged to purchase medications at the store, but small amounts of essential medications are given out by the Health Centre when necessary,

at no cost. The ability to purchase over-the-counter medications, or the lack thereof, is often a factor in decision-making.

A large portion of the population of Kugaaruk is on social assistance, and those who do work support not only themselves, but also their extended families to varying degrees. Many cannot afford to purchase medications at the store and end up visiting the Health Centre when they or family members are sick, in order to receive Tylenol. In this way, they have access to a basic product. In some cases, however, people have the resources to allow them to purchase medications, such as cold preparations, from the Co-op.

The only source of prescription medication is the Health Centre. Prescription medications are provided by Health Canada through its Non-Insured Health Benefit (NIHB) Program. This program provides First Nations and Inuit with a specified range of drugs, dental care, vision care, medical supplies and equipment when ordered by a designated health professional. This plan covers other health-related goods, such as splints, and supplies related to chronic illnesses, such as diabetes.

Personal

In addition to monetary resources, having the personal resources to deal with an illness was a consideration in health care decision-making. In my observation this was most apparent in acute and labour-intense acute illnesses in children. Acute respiratory illness in infants routinely involved feverish, cranky infants who required inhalation therapy round the clock. If infants were not in any respiratory distress, they were treated as outpatients. At such times, the nurses assessed and treated the infants several times a day, with the family providing treatment the rest of the time. On the occasions when their infants were admitted to the Health Centre, either for more intensive treatment or to await transportation to hospital, the family was to continue to assist in the care and treatment. The length of the illness, the frequency of treatments and the number of family members involved in providing care influenced decisions made with regard to seeking help and following treatment plans. When Laura's baby was kept at the Health Centre for inhalation therapy, she stayed the entire time alone with no visitors, despite having been up the night before with him. She was tired, questioned

the need for the treatments, and argued with the nurses about staying, as she wanted to go home and sleep. In contrast, when Neil's baby was kept for a similar reason, Neil was accompanied by her sister, who kept her company, and her mother came for a while so she could go home to eat and have a rest. Neil was content with her baby staying at the Health Centre until the nurses decided he could go home.

Time

Time also influenced health care decision-making: the time of day the decision was made, the timing of clinics, and the time of other activities in the community. The time of day or day of the week often influenced decisions and the actions taken. One consideration was the hours of operation of the Health Centre. Although nurses are available 24 hours a day, services after regular hours are intended for treatment of emergencies and acute illness that require medical intervention. On occasion, people sought help at the clinic, because if they self-treat and it does not work, the clinic would be closed, and they may have to wait until the next clinic day to be seen. Because the clinic was not open on the weekend, this was especially a concern at the end of the week. This was more a consideration for adults than it was for children, as in most cases children were seen after-hours if there was any chance that they were ill. Access to over-the-counter treatments at the Co-op was limited by store hours. As a result, there were times when people would seek treatment more to get over-the-counter medication like acetaminophen so they could self-treat. Gloria called the Health Centre one evening because she needed acetaminophen for her three-year-old son, who had a fever.

The time at which people sought treatment was also affected by other activities going on in the community. People did not want to miss community events, such as a hockey tournament, Christmas activities, the fishing derby and Nunavut Day activities. So whenever possible they would decide to postpone seeking treatment while these events were occurring. This often resulted in an increase in after-hour calls and very busy sick clinics once the events were over.

Values and Beliefs

A number of values and beliefs were evident in health care decision-making. The Inuit value elders as experts, and at several public meetings, the need to consult with elders on health matters was stressed by both young and old. When elders were interviewed and asked what suggestions they would give if their children or grandchildren called to ask for their advice about illnesses, such as fever, diarrhoea or cold, they all indicated that they would advise them to call the nurse. Even elders who had lost children treated by the nurse indicated that if family members asked them about being ill, they would refer them to the nurse. The nurse has become the recognized local expert and, as such, the recommended source of health care.

The value placed on children is a strong motivator for health behaviour. While the prevalence of cigarette smoking remains high in the Inuit population, smoking behaviour has changed: people no longer smoke in their homes, in order to minimize the effects of second hand smoke on the health of children. Instead they go outside to smoke. All public venues, such as the community hall, are smoke-free. Mothers indicated they had noticed a positive effect; a decrease in the number and severity of ear infections in their babies now compared to their children who were babies when people smoked in their homes.

There is a strong belief in the supernatural and spirits. Many people were able to describe a personal psychic experience, ranging from premonitions to seeing spirits. The general consensus was that everyone has these abilities, but that in some individuals, these abilities are stronger, and that these individuals could become shamans if they wished. Shamanistic healing has been replaced by biomedical medicine. The church and religion do, however, play a role, as prayer and confession are acknowledged to have a role in health. As one elder said, "Jesus does the same thing the shaman did in the past."

Knowledge

In the community, people's knowledge about their own bodies and what causes disease influenced their decisions. Knowledge of the body and its functioning influenced how people categorized symptoms, and what action they took regarding

their health. This knowledge could be based on traditional knowledge, on the understanding of the biology of animals, which was then applied to humans, or an understanding of human biology. The traditional knowledge of animal biology was more comprehensive in elders and the middle-aged than in younger age groups. The knowledge of human biology was minimal in all age groups, although those with an understanding of animal biology were able to translate this knowledge to human biology. While young people were more likely to watch movies on TV, middle-aged people favoured programming on the Learning Channel, which included programs on human biology and health and illness. People told me about watching shows on how their heart worked, HIV/AIDS and shows where surgeries were actually shown.

The decision to follow treatment was influenced by an understanding of how the treatment worked. Josh talked about watching a program on knee replacement surgery and now understands why people with arthritis sometimes require the surgery. He stated that after having seen the program, he would be more likely to have knee surgery if he was told he needed it.

Knowledge of traditional health care practices was minimal. Only after reflection were traditional treatments identified, such as the use of animal bones to splint fractures or the use of lemming skins as bandages. No one admitted using any traditional remedies today. Modern remedies were seen as being easier, more convenient and more aesthetically acceptable. No one acknowledged knowing any traditional songs for healing, and while a number of people admitted having shaman potential, no one had chosen to explore or develop this ability. In many cases, elders strongly discouraged family members from considering developing these shamanistic abilities. The main reason for this was that it was against the teachings of the church and no longer necessary. There was also an expression that the personal cost was undesirable. One woman talked about others treating shamans differently, and this was not desirable.

The school integrates health in the curriculum within other subjects, such as science. How to incorporate health into their classes is up to individual teachers. Components include self-esteem, life skills, basic anatomy and healthy living. The

Home Economics program was suspended while the new high school wing was built, as the room was needed for classroom space. Home Economics did not restart in the fall when the new wing opened, and the room was free. The Community Health Representative spoke to several classes (at the teacher's request) about smoking, and STDs. The RCMP offered their Drug Abuse Resistance Education (DARE) program for Grades 5 and 6.

In summary, numerous factors influence health care decision-making. In any single decision, numerous factors come into play and, as a result, there is a great degree of variability in the exact decision that is made. By examining the process of decision-making and the factors that influence the decision at the various stages of that process, the factors most likely to be influential can be identified. Wellness is viewed as a multidimensional concept that was equated to healthy living and included traditional values related to family, diet and the relationship to the land.

CHAPTER 7
DISCUSSION

As part of the process of carrying out ethnographic research, researchers must examine themselves and their participation in the research process and reflect on how they may have influenced the process and how the process influenced them. The researcher's background and experiences influence how they relate to participants and how participants relate to them.

Having nursed in the Arctic intermittently for over 20 years, I was well aware of the health care delivery system from the provider's perspective. Working in both the delivery of service as well as in administration broadened that perspective. The length of my nursing experience provided me with personal knowledge of the history of the health care system, and some health problems and concerns over time. It also provided contextual knowledge of the changes in health care delivery, or in some cases, lack of changes. Having experience in nursing in the Arctic also presented the possibility of bias based on that experience. This was one of the reasons I did not nurse during the data collection. By living in the community in a non-nurse capacity, I attempted to step away from the nurse role and perspective. I made a conscious effort not to be drawn into the nursing role, by either the nurses or community members.

Although not working as a nurse during the course of data collection when I was asked if I was a nurse I shared the fact that I was with participants, as this was the motivation for doing the research. Acknowledging a history with the Inuit also provided me with some degree of credibility with participants to be doing the research; however, it also may have influenced the responses from some participants. There is no way of knowing, however, whether or not this was the case.

A postpositive theoretical framework was used for this research. This research paradigm asserts that there is an objective reality; however, because of the complex and multifaceted nature of that reality, it can never be fully understood (Guba, 1990). Attempts to understand reality must be conducted in natural settings, and within the context of the phenomena being studied. The subjective, "emic," perspective of participants is acknowledged as a legitimate source of data. The researcher is

acknowledged as a participant in the research process and therefore not entirely objective to the data (Racher & Robinson, 2002; Clark, 1998). In the acknowledgment that objectivity might not be possible, findings are verified with participants. The contextual nature of findings limits their generalizabilty outside the context or situation of study. This framework is consistent with ethnographic research, which relies on the researcher participating and interacting with the research population in a contextual situation.

Health Care Decision-Making Processes

Two health care decision-making processes were identified from this research: the illness management decision-making process used in dealing with illnesses, and the health promotion/prevention decision-making process, dealing with health promotion and disease

The illness management decision-making process of the Inuit is composed of five decision points, a number of which are similar to those recognized by Brink (1977) and Twaddle (1979):

1. Deciding a person is ill
2. Deciding on the severity of the illness
3. Deciding to seek treatment
4. Deciding to follow treatment
5. Deciding a person is well

Similar to the findings of Brink (1977) and Twaddle (1979), an initial decision was made that the person was ill. The severity of the illness was determined as suggested by Twaddle, and then the decision was made whether or not to seek treatment. The decision to follow through with treatment is similar to Brink's fourth decision with respect to remaining with the healer, and Twaddle's cooperating with treatment. The final step, deciding the person is well, was consistent with Brink's final step. In short, the process of illness management care decision-making of the Inuit is very similar to Brink and Twaddle in four of the five decision points. There were two significant differences at the third decision point, "deciding to seek treatment," with regard to where and when to seek treatment.

The Inuit have no choice regarding where to seek treatment. The Health Centre is the only resource. Presently no Inuit healers or healing practices are used. Services provided at the Health Centre are focused on physical illness treatment, illness prevention and health promotion. Only minimal services are available in the community for mental health problems, which include a Help line, a list of community volunteers, and a community wellness worker who is available to talk to people in crisis. This is significantly different from Brink (1977) and Twaddle's (1979) findings. In both Brink's and Twaddle's work, people had choices regarding where and from whom to seek treatment. People made the choice of healer based on resources, accessibility, experience, and comfort level.

The choice of when to seek treatment in relation to other activities is also unique. Brant (1990) describes a native ethic around time, which is based on doing things when the time is right, the right time being determined not by the time of day or hours of operation but based on the right time with regard to the environment and social context. This is consistent with the socio-environmental context of the Inuit. Community activities are festive times and often occur during the winter, when life is stressful as people are confined in overcrowded homes. In my own research (Edgecombe, 1994), I found the Inuit to be present oriented, thus supporting a tendency to live in the moment. When these activities occur, the time is right to go to them. In the summer, if the weather is fine, it is the time to get out and enjoy the land and its bounty. Health care is in competition with other activities. Neither Brink (1977) nor Twaddle (1979) indicated any consideration of time conflicts in their research.

Decision-making related to health promotion and disease prevention consists of four decision points:

1. Deciding a person is well
2. Deciding to participate in a health promotion activity
3. Deciding on the presences of a potential threat
4. Deciding to access services and/or change behaviour.

This process is consistent with several of the health promotion models. Similar to the Health Belief Model (Becker et al., 1974; Becker et al., 1977) and the Protection Motivation Model (Pender, 1996; Plotnikoff & Higginbotham, 1998), health promotion/prevention decision-making is linked to the perceived seriousness of the risk and perceived susceptibility to it, and is influenced by knowledge, past experience and sociocultural factors.

Influencing Factors

Both illness management decision-making and health promotion/prevention decision-making are influenced by factors similar to those identified by Cox (1982) as being background variables that affected client behaviour in the Interaction Model of Client Behaviour (i.e. social influence, previous health experience and environmental resources). The types of general factors that influence health care decision-making are not unique, but the nature and specifics of those factors are.

Kugaaruk is situated in an Arctic environment, which underlies all decisions, including health care decisions. Both geographical isolation and lack of resources limit choices to any alternative other than the services provided by the nurses at the community Health Centre. People can choose to self-treat; however, the options for self-treatment are limited by what is available within the community and the resources available to the individual. The nurses themselves are limited in the treatment they are able to provide, due to the resources available to them. There is no mechanism through which the nurses can obtain alternative therapies for patients, and therefore they are, by default, compelled to treat patients using what is available to them.

Inuit experiences are significantly different from those of Canadians in other areas of the country. Until the 1960s, they maintained their traditional lifestyle of living in igloos and skin tents. They traveled in family groups, following a hunting cycle, dependent on the game available. With the establishment of settlements in the 1960s came schools, health services and a technological revolution. English is a second language, and many people over 60 do not speak English. This rapid transition from traditional to modern living has resulted in a familiarity with modern conveniences, while maintaining a respect for tradition and traditional understanding

of the world. Health and wellness remains strongly associated with traditional values, such as a relationship with nature and the land and maintaining strong social relationships. Yet, the biomedical health care system is strongly established as the norm for health care and people are used to visiting major health centres, such as Edmonton, Alberta, for advanced and highly technical health care.

Past experience with certain illnesses is also somewhat different from the southern regions. The morbidity of certain diseases differs from other ethnic groups, as does the environment in which that morbidity occurs. Most health professionals are from the south and are often unaware of these differences or their implications for health care and health promotion programs. The concern parents have for upper respiratory infections in small children, especially in the spring, could be misinterpreted as overuse of the health care system, until the incidence and presentation of bronchiolitis and RSV infections is considered.

The media has allowed the Inuit to become more aware of what is happening in other parts of Canada and the world and has the potential to influence behaviour. In some cases, it did seem to influence health care decision-making with regard to prevention. While a flu outbreak and death in another regional community did seem to have an influence on some people to seek immunization, the media was only one factor involved. It has exposed them to information on other treatment alternatives and health information about illness and health promotion. There was no indication that people were seeking treatment or requesting health products for illnesses based on information they had obtained from the media, such as drug commercials. While SARS was a major news item during my time in the community, no one sought health care with a concern about having SARS, although there was concern expressed by community leaders and health professionals about how an infection like SARS could be managed in Kugaaruk.

Traditional values and beliefs about health and wellness, such as the value of country foods (such as char and caribou) and connection with the land, are respected and encouraged by middle-aged and older adults. At community functions, country foods such as char and caribou were served, and activities related to land skills were

incorporated into the curriculum at the local schools as much as possible. There is a paradox regarding the emphasis on traditional knowledge and beliefs, on one hand, and the almost total reliance on the biomedical system for health care, on the other. The Inuit are firm in their desire to maintain and promote their culture, and this is apparent in government initiatives, discussions at public meetings, school curricula and the Inuit media. In contrast, the biomedical system is accepted as being the main method of health care.

There are several reasons for this paradox. With the arrival of Qallunat (non-Inuit) in the early 1900s came numerous communicable diseases (i.e. tuberculosis and measles), for which existing Inuit remedies and shamanistic healing were ineffective. Biomedicine was also introduced at this time, first by the missionaries and later by the introduction of Nursing Stations at a local level. Initially, missionaries would have treated people locally with basic supplies, but as transportation to the north improved, people with communicable diseases were evacuated to hospitals. Over time, shamanism was abandoned, local remedies were replaced with biomedical medications, and a reliance on the biomedical model developed, even when self-treating using over-the-counter drugs. As the north became more accessible from southern Canada, with the influx of southern practitioners, the south became more and more influential in the policies of northern health care. Southern standards, such as the recommendation of hospital deliveries, were implemented throughout the north without consideration of their appropriateness or desirability (O'Neil & Kaufert, 1995).

Medical Services

The community Health Centre clinic is administered by a regional office of the Department of Health and Social Services. It is open on weekdays, from 0830 to 1700, with sick clinics every morning. While people with emergencies and serious illnesses are seen regardless of the hour, the nurses determine whether an illness is serious enough to be seen outside of the sick clinic hours. As a result, there are times when individuals and/or their families decide they are ill and require treatment by the nurse, but the nurses, in their assessment, determine they should wait until the next regular

clinic to be seen. Nurses are discouraged from seeing people after hours, by an organizational policy that only young children and emergencies should be seen after hours. The Health Centre complement of two nurses has been the same for over 20 years, despite an increase in the population overall and of the elderly, and an increase in patient morbidity. Regional departmental staff acknowledge that staffing allocation at all levels is a problem, but funding for extra staffing is not available. The nurses work long hours and need to establish limits, for their own mental and physical health.

There is an overall emphasis by health professionals on promoting self-care among the Inuit. At times, this emphasis on self-care causes tension and conflict between the sick person, the family and the nurses. It is the nurse, not the client, who decides what should be self-treated. The nurse, because of policy and workload, may refuse to see people after-hours even if they feel they have a valid reason to be seen after-hours. It is only when the client acts in concert with the nurse regarding self-treatment that they are considered to be independent. Clients base their concerns and expectations on their level of knowledge and/or experience with the illnesses or symptoms, which may be different from the health professional's. What may to the nurse be minor and not needing to be seen may seem very different to the client or family. In fostering true independence the system needs to allow people the ability to make a health care decision and to act on that decision, including the decision that they want to be seen. That cannot occur with the current staffing and organization of the Health Centres.

Since there are few resources available, the Inuit are denied alternatives available to other Canadians. Only a very limited number of over-the-counter drugs and medication alternatives (i.e. vitamins, herbal remedies) are locally available, and no alternative treatments are available. In contrast, in many southern Canadian cities, access to over-the-counter drugs and alternative over-the-counter therapies are available at drug stores that are open during the evenings and on weekends and, in some places, 24 hours a day. Similarly, in southern Canada, people have access to medi-centres and emergency rooms 24 hours a day if they are feeling ill and do not mind a long wait before they are seen. In southern Canada, a multitude of alternative

treatments are available: chiropractic services, acupuncture, physiotherapy, massage and homeopathy, to name a few. In some provinces, some of these alternatives have become ordinary and are covered, in whole or in part, by the provincial health care plan. In addition, there are health food stores and large alternative medicine sections in drug stores.

More and more alternative therapies are explored and promoted in the media. Many television programs discuss the merits of well-established therapies. The presence of Echinacea and Vitamin C in the Co-op indicates that there is interest in alternative therapies when they are available. The number of people using these options is small, because of the costs and the limited selection available at the local store. A large percentage of the residents are on social assistance, and these options are beyond their financial means.

Traditional practices are also beyond the average person's reach. Even if an individual wanted to consult a shaman about an illness, there is no local shaman. The nearest one I was able to identify was in a community 800 kilometres away. The airfare for a consultation is beyond the means of the majority of the population.

The Inuit concept of health identified in this study is consistent with concepts identified by Shea (1988) and Stairs (1992), with health being described in holistic terms, including not just physical well-being but also social, spiritual and mental well-being. Individual health is linked to traditional activities and values, especially diet and spending time out on the land. An emphasis on social relationships and avoidance of harmful activities, such as substance abuse and gambling, was also expressed. Inuit elders emphasized that the young needed to connect more with the land and learn traditional skills such as hunting. They equated these activities with developing skills that would lead to healthier individuals. While young people still express an association of wellness to country foods, a connection to the land and social cohesiveness, they are less likely to engage in activities that express this belief. On one occasion the elders, teachers and senior students at the high school planned and organized a snowmobile trip to another community, which was to have taken two

days. The trip was cancelled after four hours, however, as the young people wanted to return to the community.

Recommendations for Health Policy and Services

An understanding of how and what decisions the Inuit make about health care, both preventative and curative, should have implications for both health policy and health services for the Inuit. Such knowledge could result in culturally appropriate health promotion activities and could increase their effectiveness. Health promotion can incorporate Inuit values, such as a connectedness with the land, country foods (caribou and char) and Inuit social cohesiveness. Nunavut is a new political jurisdiction with the goal of delivering services and policies congruent with the Inuit culture and society, which includes incorporating Inuit health beliefs and practices, where appropriate, into the health care system. The results from this study may provide information that will assist in the development of both a culturally relevant health policy and a health care system that meets the needs of the Inuit population. Elders have expressed a desire to be involved in health promotion, and this needs to be encouraged in developing public policy, education curricula and the health care system.

An understanding of how and why the Inuit make health care decisions can result in nurses and other health care providers responding to those decisions based on understanding rather than on potentially erroneous assumptions. In this way, nurses and other health professionals can then better respond not only to the reasons for the interaction, but also to the reasoning that initiated the interaction. Further, nurses and other health professionals can liaise knowledgeably with the informal care network, whether it consists of family or other service providers, to help provide consistent, effective, and culturally appropriate services.

Prenatal health care is one such area where policy could be changed. An alternative to the current use of prenatal vitamins would be to provide only those elements proven to be effective, such as folic acid, calcium and magnesium (Health Canada, 1996). Elders could be involved in prenatal programs to promote healthy pregnancies. Prenatal programs are offered at the Health Centre as well as in the

Hamlet through the federally funded Prenatal Nutrition Program. At this time, these programs, for the most part, operate totally separately, partly because of funding requirements. There needs to be stronger partnerships between these programs so that they complement and support each other.

Another area to be explored is the development of midwifery services within Nunavut. Midwifery services could be expanded by operating birthing centres in all larger communities and utilizing lay midwives and *dulas* in smaller communities, with the aim of allowing low-risk prenatal women who want to deliver in their home communities, and are aware of the risk, to do so. For women who do leave the communities for delivery, Tele-health equipment could be used to allow them to have audio-visual contact with their families.

Consideration must be given to workload and the work-life issues of the staff working in Health Centres. Currently nurses are imported into Nunavut and are primarily there to work hard for at most a few years, and then leave. In 2004, Nunavut Arctic College, in collaboration with Dalhousie University, began graduating Inuit nurses who will not only be working in the community, but also be part of the community. They will have family and community responsibilities beyond their jobs, and the current organization of health services will become even more problematic. The administration of the Health Centres is bureaucratic, and the hours of operation are established by convention rather than community consultation. Policies are made either at regional offices or the head office of the Department of Health and Social Services and do not necessarily meet the needs of either the clientele (i.e. hours of operation) or the staff (i.e. complexity of drug ordering). The existing system needs to be reviewed, with consideration as to how work can be simplified for front-line workers, and how services can fit into community needs and way of life. This may include having nurses who work regular hours and others that cover after-hour calls, with more flexibility to see people who require assistance but who are not considered emergencies by the biomedical definition.

Physician visits could be utilized more effectively. For example, consultation about the patients could be done via phone before and after visits. This would allow

the physician to order lab work prior to his/her visit so that the results are available at the time of the visit, and to do follow-up before the next visit, with the aim of eliminating delays in diagnosis and treatment. Internet charts and information sharing should also be explored.

Developing programs in which elders and their knowledge could be utilized to promote healthy living and traditional social and life skills would serve several purposes. By sharing and teaching traditional skills, the elders could foster self-esteem and cultural pride, while enhancing cultural values. The act of utilizing elders and traditional skills and values within the health care system sends a message that supports the value of traditional knowledge and values. Traditional values have been found to contribute to the Inuit concept of health and wellness (Shea, 1988; Stairs, 1992).

The problem of addictions (alcohol, drugs and gambling) is complex and must be approached in a variety of ways. Treatment centres must be accessible, and where possible, programs should include family. On return to their home communities, people require support to assist them to form and maintain peer groups that are not centred on addictive behaviours (Brady, 1995). Many aboriginal groups have developed successful programs, utilizing cultural values and beliefs to promote resiliency in the individuals and to foster structured community support following treatment (Brady, 1995; Dell, Dell, & Hopkins, 2005). Program development for the Inuit needs to identify Inuit cultural practices that may be utilized in the healing process. Drum dancing and singing is one possibility. Traditionally, drum dancing and song were used as a mechanism for expressing strong emotions, resolving conflict and clearing the air (Balikci, 1970; Rasmussen, 1976). Nunavut Arctic College has established a mental health worker program, and graduates at the community level could assist in developing and maintaining support for individuals recovering from addictions. The use of both treatment facilities and community development will facilitate individuals to develop coping skills within a controlled environment and continue to be supported on return to their community.

There are many events which have affected the Inuit, such as the rapid socioeconomic changes of the passed 80 years, and residential schools. The resulting mental health problems, such as family violence are not being addressed adequately. While there are a few services in some larger centres, such as woman's shelters and counseling services, there are minimal if any services in most communities. The development and utilization of community level Inuit mental health workers will support the developing and maintaining programs to address local mental health problems.

Implications for Nursing

Clearly, the nurses are respected as health care providers. Elders, when asked, advised people to seek help from the nurses. Traditional Inuit culture was based on utilizing experts and their knowledge. Over the years, I have learned that the best hunter would be consulted about hunting; the best fisherman would be consulted about fishing. Even experienced hunters and fishermen did this, out of respect for the expertise and knowledge the other possessed. It may be that in the same manner people consulted with the nurses. Nurses need to be aware of the role they play and consider the implications for their practice. They need to consider that people may seek their counsel as much because they are viewed as an expert as because the person needs care.

The differences in morbidity and prevalence of some disorders in the Inuit population must be acknowledged and incorporated into treatment regimens. For example, Inuit children under the age of five years are more likely to have an *otitis media* infection than non-Inuit children, and many of these infections become chronic (Bowd, 2005). Poor nutrition may be a factor in this disorder (Jones & Smith, 2006). Treatment regimens should include a nutrition component and, if necessary, supplementation. With this comes a need to consider family and community histories in assessing not only risk, but also psychosocial responses to illnesses.

Health promotion and preventative activities need to be evaluated in the light of the values and beliefs associated with them and, where possible, to incorporated these beliefs and values. By working with Inuit beliefs and values, changes in

behaviour are more likely, and there may be an increased likelihood that treatments will be followed. This is illustrated by the smoking practices in the community. The value placed on children has resulted in people no longer smoking indoors and at community functions. This change was in response to the health promotion campaign that linked secondhand smoke to respiratory and ear infections in children.

Access to non-prescription remedies, health promotion material and alternative treatments is limited and a barrier to self-care. Nurses, however, can be more sensitive to "being out on the land" as a healthy alternative, both mentally and physically. In addition, country foods could be encouraged to a greater extent. Nurses need to be advocates for the use of alternative treatments when possible within the health care system and should encourage their availability at both the Health Centre and the local store. While the policy of not providing over-the-counter drugs may be a good one with regard to not fostering dependency, it does not acknowledge the limited accessibility or the financial reality of the large numbers of families dependent on social assistance, who cannot afford to purchase what they consider non-essentials, such as vitamins and over-the-counter remedies.

The work force at the Health Centre has remained unchanged since the mid 1980s, over 20 years ago. The community has grown from 297 (Statistics Canada, 1987) to 605 (Statistics Canada, 2001e). With this increase in population, there has also been an increase in patient acuity. As a result, the nurses' workload in acute care has increased dramatically and in order to cope, health promotion activities have decreased. Even so, nurses work long hours and under considerable stress. While there are more community initiatives, such as the prenatal nutrition program, the nurses are often unable to provide support to the lay workers delivering the programs. Nurses should be available as resources to these programs, but all too often, they find themselves unable to be involved due to workload conflicts.

A review and analysis of Departmental and Regional policies and procedures related to service delivery and workflow would be useful. There needs to be a commitment to staff Health Centres at a level that allows the nurses to focus more on health promotion and to be involved in the community. Administrative tasks need to

be evaluated for effectiveness and efficiency from the care provider and client perspective, in an effort to have a system that works better and is more easily managed.

Most nurses are from the south or outside the north and are content to make work their total existence—but only for a short time. This does not promote retention and will be problematic as Inuit nurses join the work force and have family and community responsibilities outside their jobs. Alternative ways of organizing the workload and demands necessary to provide 24-hour services to the community need to be developed. Communities themselves need to be involved in this process and the system must be flexible enough to allow more than one alternative, as community size, resources and needs vary. Possibilities include introducing staff to perform administrative duties now being done by nurses; having dedicated staff on call evenings, nights and weekends; and hiring seasonal nursing staff as extra staff during spring/summer, when the incidence of bronchiolitis is high, which could allow more on site-treatment without extra demand on staff.

Limitations

The health care decision-making process varies depending upon the particular individuals, families or situations. These variations are the result of the influencing factors that come into play in that particular situation, at that particular time, with that particular person(s). Healthcare and health prevention/promotion decision-making processes do not predict behaviour, but do provide clarification of the possible reasons for the behaviours related to the decision-making. While the findings of one study in one community may not be applicable to all Inuit, there are enough similarities between communities to suggest that there are grounds for some generalizations. The organization and operation of Health Centres and health services are standardized, with very little variation across Nunavut. The incidence and prevalence of illnesses and disease also does not vary greatly across Nunavut. The association of health and wellness to country foods, a connection with the land and social cohesiveness is documented from various areas of the north (Shea, 1988; Stair, 1992). The government established all settlements in Nunavut, at times with a distinct political

agenda, especially in terms of location. Along with this came government intrusion into many aspects of Inuit life through policies and regulations (Tester & Kulchyski, 1994; Fletcher, 2004). The resulting systems, including health care, exist universally across the north today. While there are social variations between Inuit groups, the services that are provided are structurally the same and are likely to be problematic.

Interviews with elders were conducted with an interpreter and some information and meaning may have been lost in translation. An attempt was made to minimize this by using only one or two interpreters; however, this was not always successful.

Future Research

Further research related to health care decision-making is suggested. Comparing the decision-making process identified in this research with other Inuit groups could validate these findings. While there are similarities between Inuit, there are also differences, and these differences may affect either the decision-making process and/or the factors that influence the process. The identification of other influencing factors can be used to understand health behaviour and/or utilization of the health care system.

Research into the health issues and practices of the Inuit is limited. During this research study, it became evident that further investigation into the classification and schema of illnesses is necessary. How do the Inuit label and define symptoms, and how do they link these symptoms together to identify illness? While people readily seek consultation with the biomedical system, what are their expectations from both the system and the treatment regimens?

Mental health is a significant problem in many Inuit communities. Resources are extremely limited and impersonal. From descriptions of shamanistic practices, there was an element of psychotherapy through the public confession of a lie or secret, enabling the person to vocalize something that was bothering him/her and, through this disclosure, move on. This seems to indicate that activities such as healing circles may be useful tools for addressing at least some mental health problems. Research as to the appropriateness and effectiveness of healing circles should be considered.

Further exploration of the utilization of elder knowledge in health promotion is another area of research. What are the traditional practices that promote health, and how can they be incorporated into modern Inuit society? As many of the elders who actually live the traditional way are of advanced age, this area of research needs to be conducted in a timely manner.

Finally, what are the implications of the workload on the nurses for staff retention, nurse and patient satisfaction and nurse performance? Are there alterations to health services delivery that would have a positive effect on workload, and what are the implications?

The health care decision-making process of the Kugaaruk Inuit, as with other groups, is a complex cultural mosaic based upon environment, economics, values and beliefs, past history and government policy. The Inuit are a pragmatic people, making do with what they have, and what they have is limited. They value their children and the health of their children. They value their contact with the land with an almost spiritual connection. They value experts and seek their advice. The existing formal health care system is based on a biomedical model that focuses on illness and cure rather than health and wellness; the acute more than the sub-acute. To the greatest possible degree, providing the Inuit with more alternatives within the context of their current limitations is imperative, as is restructuring the health care delivery system. They need more options and support systems to help the community empower itself.

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APPENDIX A: RESEARCH NOTICE

My name is Nancy Edgecombe and I am a student at the University of Alberta. I am here in Kugaaruk to do a study to learn about the decisions the Inuit make about their health care, and why they make these decisions. I believe this information will help non-Inuit health care workers to understand the Inuit and their culture in regards to health better.

To do this study I will be living in Kugaaruk meeting people and talking with them about their health their health care activities.

- No one will know that you have talked to me.
- All information discussed, will be kept private.
- All data and information gathered will be locked in filing cabinets.
- Only I will have access to the information.
- No information about your identity will be used in reports or articles that will be written.
- A final report will be provided to the Hamlet council.

I am going to be talking to a lot of people while I am here. If you do not want to talk to me you don't have to.

If you have any questions about this study, you may call me at XXX-XXXX or my supervisor Dr. P. Brink in Alberta at (XXX) XXX-XXXX

APPENDIX B: INFORMATION LETTER FOR PARTICIPANTS

Title of Project: Health Care Decision Making of the Inuit

Investigator: Nancy Edgecombe, RN, MN,
PhD Candidate
Faculty of Nursing
University of Alberta
Edmonton, AB T6G 2G3
Phone: XXX-XXXX

Dr. Pamela Brink, RN,
Supervisor
Faculty of Nursing
University of Alberta
Edmonton, AB T6G 2G3
Phone: (XXX) XXX-XXXX

Purpose: I am doing this study is to learn about how the Inuit make health care decisions.

Procedure: I would like to interview you to discuss and ask questions about your experiences with health and illness. I may need to talk to you more than once to clarify what you have told me.

- Each interview will last from 30 to 60 minutes.
- The interviews will be tape-recorded.
- You may choose at any time not to talk to me or to not answer any questions.

Risks And Benefits:

- There are no anticipated/known risks to you or your family for being in this study.
- There will be no direct benefit to you or your family for being in the study.
- Your information may help nurses, other health professionals and health authorities working with the Inuit.

Statement of Confidentiality:

- I will not tell anyone that you have talked to me.
- All information discussed, written notes and tape recordings, will be kept private, except when professional codes of ethics and/or legislation require reporting.
- No names will be written on the tapes or transcripts. Only a code number will be used.
- The consent forms, written notes, tapes and transcripts will be locked in filing cabinets. Only I will have access to the information.
- No information about who you are will be used in reports or articles that will be written.
- Something you said may be quoted, but no one reading the information will know it is you.

Freedom to Withdraw: You may change your mind about being interviewed at any time. If you decide not to be interviewed, this will not affect the care you in

any way. To withdraw, please contact one of the people whose name is on this letter.

A Final report on this research will be provided to the Hamlet Council

Future Research: The information gathered for this study may be looked at again in the future to help answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically.

Contacts: If you have any questions about this study, you may call Dr. P. Brink at (phone number) or Susan Woodley at the Nunavut Research Institute (phone number)

_____ _____

Initials Subject Initials Researcher

APPENDIX C: INFORMED CONSENT – FORMAL INTERVIEWS

Investigator: Nancy Edgecombe, RN, MN, PhD Candidate
Faculty of Nursing
University of Alberta
Edmonton, AB T6G 2G3
Phone: (XXX)XXX-XXXX

Dr. Pamela Brink, RN, PhD
Supervisor
Faculty of Nursing
University of Alberta
Edmonton, AB T6G 2G3
Phone: (XXX) XXX-XXXX

	Please circle one	
Do you understand that you have been asked to take part in a research study?	Yes	No
Have you received a copy of, and read the Information Letter (attached)?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss the study?	Yes	No
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect you in any way.	Yes	No
Has confidentiality been explained to you?	Yes	No
Do you understand what it means?	Yes	No
Do you understand who will have access to the information you provide?	Yes	No

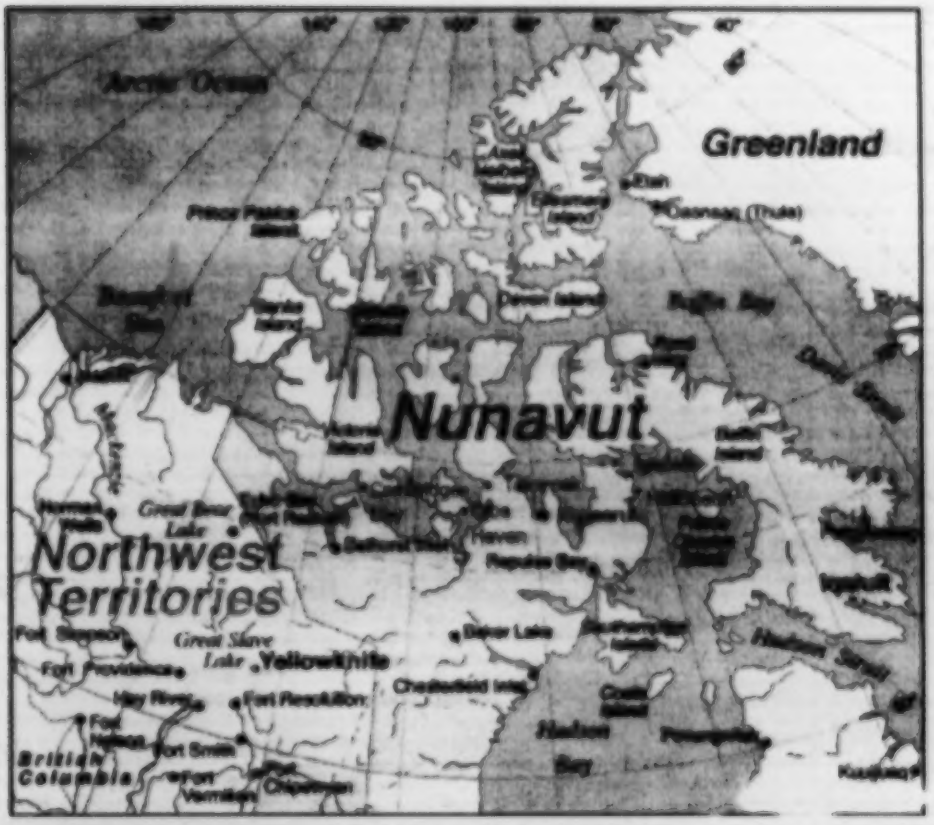
This study was explained to me by:		
	Name of person	Date
I agree to take part in this study:		
	Signature of research participant	Date
	Printed name	
	Signature of witness	Date
	Printed name	
I believe the person signing this form understands what is involved in the study and voluntarily agrees to participate.		
	Signature of Investigator	Date

* A copy of this consent must be given the subject

APPENDIX D: INFORMATION – INFORMAL INTERVIEWS

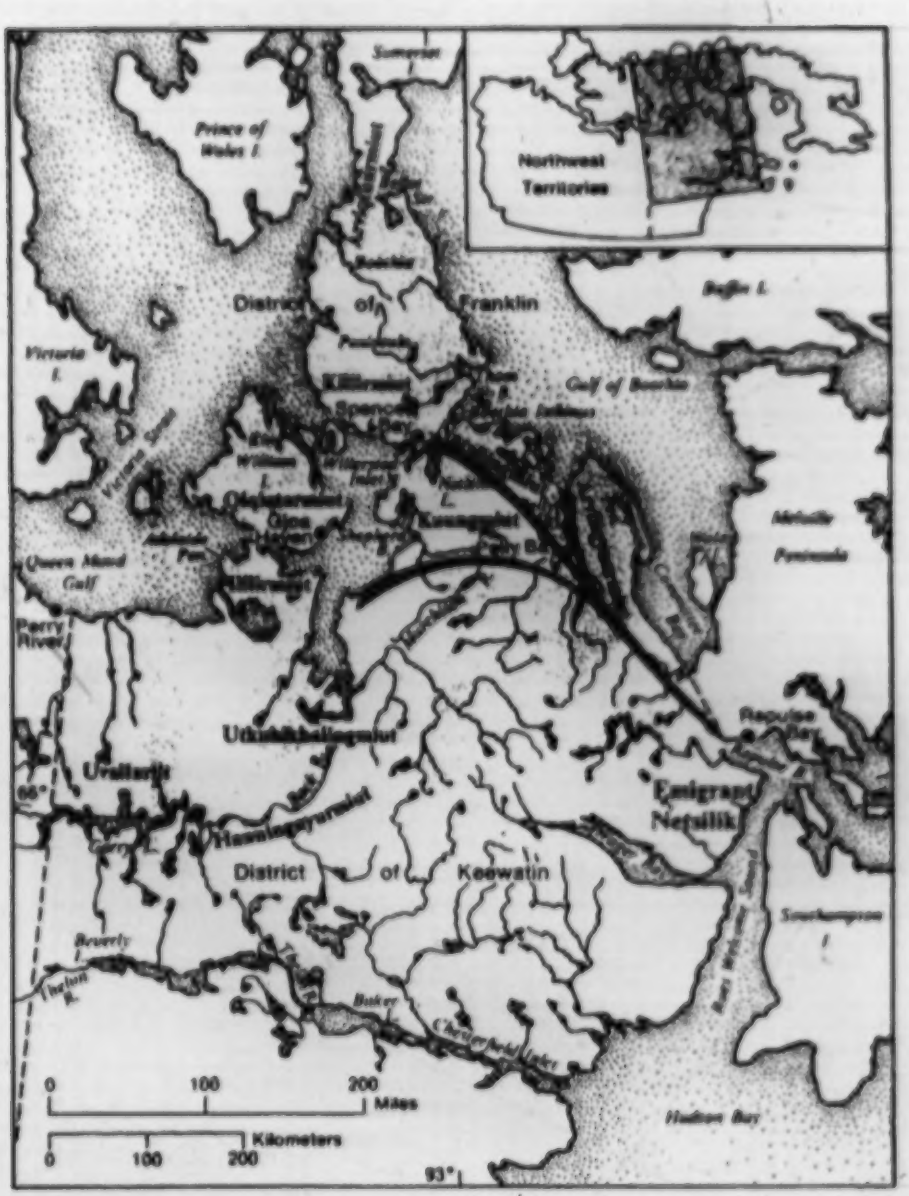
My name is Nancy Edgecombe and I am a student at the University of Alberta. I am here in Kugaaruk to do a study to learn about the decisions the Inuit make about their health care, and why they make them. I believe this information will help non-Inuit health care workers to understand you and your culture better. Would you be willing to talk to me about {topic to discussed} Would you like more information about being in this study.

APPENDIX E: MAP NUNAVUT



Adapted from Infoplease (n/a) Map: Nunavut. Retrieved June 24, 2006 from http://www.infoplease.com/atlas/region/nunavut.html

APPENDIX F: NETSILIK INUIT 1860 TO 1920



Balikci, A. (1984). Netsilik. In D. Damas (Ed.), *Handbook of North American Indians: Arctic* (Vol. 5). Washington, DC: Smithsonian Institute.

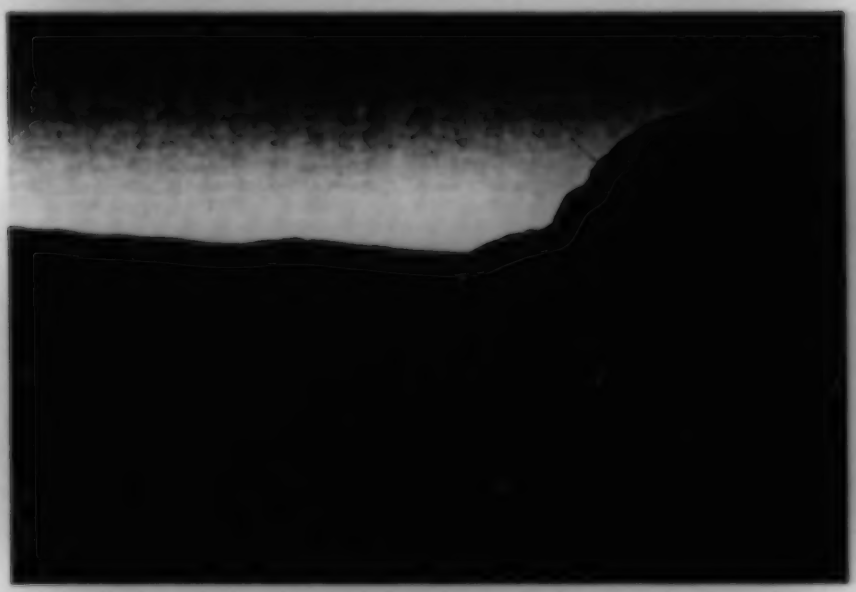
APPENDIX G: COMMUNIY PICTURES

The Hamlet of Kugaaruk

People returning to work and school after lunch

Houses along shore

Newer homes



Kugaaruk River

School

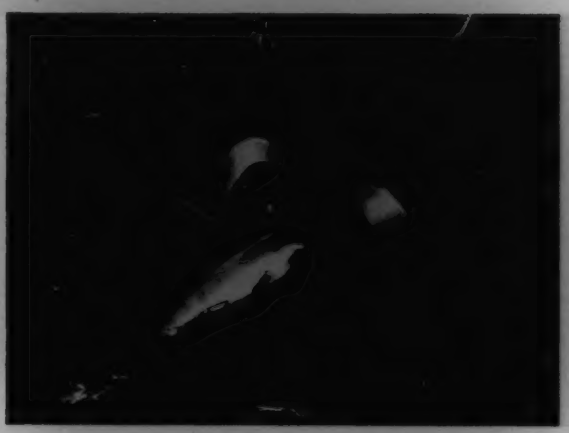
Original stone church

Communal marker old grave site

Old grave sité by stone church

Qulliq (seal oil lamp)

Fire truck - part of Canada Day parade



Woman filliting fish with ulu (woman's knife)

Main street in Kugaaruk

Crossing a spring melt off on ATV

Truck on road

SkiDoos and ATV after a storm

Out on the land

Unpacking sealift crates at CO-OP

Sunset over town

Boys playing on ice forming in fall

Sealift ship